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ABSTRACT

The proceedings of this 1984 hearing presents recommendations to improve services for mentally retarded citizens. A report on conditions in intermediate care facilities for the mentally retarded is followed by statements of Senators L. Weicker, Jr., J. Randolph, and R. Stafford and by the Secretary of the U.S. Department of Health and Human Services (M. Heckler). Statements are also presented by the American Health Care Association, T. Gilhool (Public Interest Law Center of Philadelphia), C. Davis (Health Care Financing Administration), and R. Melzer (Vermont Department of Mental Health). Responses are included to questions by the committee on such topics as sheltered workshops, Medicaid funding, investigation of abuse and neglect in institutions, and deinstitutionalization. (CL)

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S. HRG. 98-1045

SERVICES FOR MENTALLY RETARDED PERSONS

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JOINT HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON LABOR AND HUMAN RESOURCES

AND THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

OF THE

COMMITTEE ON APPROPRIATIONS UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

SECOND SESSION

ON

RECOMMENDATIONS TO IMPROVE SERVICES FOR MENTALLY RETARDED CITIZENS

JULY 31, 1984

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SERVICES FOR MENTALLY RETARDED PERSONS

TUESDAY, JULY 31, 1984

U.S. SENATE, SUBCOMMITTEE ON THE HANDICAPPED OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES, AND SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES OF THE COMMITTEE ON APPROPRIATIONS,

Washington, DC.

The subcommittees met, pursuant to notice, at 10:45 a.m., in room SD-430, Dirksen Senate Office Building, Senator Lowell Weicker, Jr. (chairman of the subcommittees) presiding.

Present: Senators Weicker, Thurmond, Nickles, and Stafford.

OPENING STATEMENT OF SENATOR WEICKER

Senator WEICKER. The subcommittee will come to order.

Today the Subcommittee on the Handicapped and the Subcommittee on Labor/HHS/Education meet jointly to consider recommendations to improve services for mentally retarded persons.

Last November the Subcommittee on the Handicapped held a hearing to examine the Department of Justice's record of enforcement of the civil rights of mentally retarded persons in institutions. The facts presented in that hearing confirmed instances of the grossest forms of abuse and neglect in federally-funded institutions across the country.

Despite this overwhelming evidence, the Department of Justice had not filed suit against any of the institutions, but had chosen to "negotiate" while our mentally retarded citizens continue to live day after day in life-threatening situations. These are institutions which are supported by $2.3 billion Federal dollars per year.

In the face of such evidence, I sent staff from the subcommittee out across the country to visit institutions to get a firsthand look at the conditions in which over 180,000 of our Nation's mentally retarded citizens live, and today I place my staff's report in the hearing record.

[The staff report referred to follows:]

United States Senate Subcommittee

on the Handicapped

Report to the Chairman
Senator Lowell Weicker, Jr.

July, 1984

CONDITIONS IN INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED

I INTRODUCTION

On November 17, 1983 the U.S. Senate Subcommittee on the Handicapped, chaired by Senator Lowell Weicker, Jr., held a hearing to review the U.S. Department of Justice's record on enforcement of the civil rights of mentally retarded persons in federally funded institutions. Evidence was presented at that hearing which documented widespread neglect, abuse and other conditions of substandard care in federally funded institutions across the country. As a result of the information presented at that hearing Senator Weicker instructed his staff to conduct a series of site visits to institutions for mentally retarded persons to gather information about conditions in those facilities.

Seven institutions, all of which are public certified Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), were visted by Senate staff during December 1983

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and January 1984. All institutions chosen for site visits were large (400 beds or more) and located in the varying geographical regions of the United States. Institutions were selected which represented varying degrees of involvement (both historically and currently) with the U.S. Department of Justice, the courts and the U.S. Department of Health and Human Services. The range was distributed from a very high degree of involvement to no involvement other than routine annual certification surveys. The sample of institutions visited included institutions as old as 100 years and as new as 10 years.

The site visits were not intended to focus on the quality of any particular insitution nor to respond to allegations made about any specific institution. Rather, the intention was to observe the ICFMR institution programs to determine in a general way whether or not substandard conditions exist and the extent to which they persist from one institution to another.

II BACKGROUND OF THE ICFMR PROGRAM

STATUTORY AUTHORITY

In 1971, title XIX of the Social Security Act (Medicaid) was amended to authorize States to include in their State Medicaid plans services to institutionalized persons with

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mental retardation. Such services, referred to in the statute as "intermediate care facility services," are authorized if the primary purpose of institutionalization is to provide health or rehabilitative services. The service must meet standards prescribed by the Secretary, and the mentally retarded persons are to receive active treatment under this program. This law requires that States provide for a program of independent professional review, including medical evaluation of the need for care of each person served, as well as a written plan of service which provides more than a minimum level of health care for each such person. The review is to include periodic on-site inspections of each institution and of the care provided therein. The review team, including physicians, nurses and other health and social service personnel, is to review the adequacy of services provided to meet the health needs and promote maximum physical well-being of persons receiving care. The team is also to determine the necessity of continued institutionalization and the feasibility of alternative placement.

As with all Medicaid services, States may include ICF/MR services as part of their State Medicaid plan. Federal ICF/MR funding is provided through an open-ended entitlement. That is, States are not limited to the amount of federal funds they may receive as long as they meet standards and provide the required matching funds.

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ICF/MR REGULATIONS

In 1974, the Secretary published regulations which prescibe standards for services in (ICFs/MR). The regualtions set forth standards for administrative policies and procedures, personnel policies, resident living standards, and professional and other services. A major feature of the ICF/MR standards is that the standards generally assume the delivery of services within the institutions. However, agencies or individuals outside the ICF/MR that meet service standards are also authorized to deliver services, by contract, within the ICF/MR. Services to be provided to institutionalized persons include dental services, training and habilitation, food and nutrition services, medical services, nursing services, pharmacy services, physical and occupational therapy, psychological services, recreation, social services, and speech pathology and audiology services. The regulations also establish standards for safety and sanitation.

The ICF/MR standards for resident living include provisions regarding the rights of institutionalized persons. The ICF/MR is to have written policies and procedures which insure the civil rights of all residents. Residents are to be treated with consideration, respect and full recognition of their dignity and individuality. The standards do not allow the use of physical restraint unless absolutely

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necessary or unless such restraint is part of a behavior modification program. Physical or chemical restraint may not be used as punishment, for the covenience of the staff, or as a substitute for treatment or activities. The standards provide that chemical restraints may not be used in quantities that interfere with a resident's habilitation program.

The regulations make provision for small ICFs/MR of 15 beds or fewer by making different fire protection requirements for such facilities.

THE MEDICAID WAIVER

In 1981, title XIX was amended to allow the Secretary of Health and Human Services to approve the use of Medicaid funds for home and community-based services for the aged, the physically disabled, the mentally retarded and the mentally ill. Under an approved waiver, services, other than room and board, may be provided to mentally retarded persons who, but for the provision of such services, would require the level of care provided in Medicaid-supported institutions. Regulations implementing the waiver provision authorize case management services, homemaker/home health aide services and personal care services, adult day health, habilitation services, respite care services and other services as approved by the Secretary. States may be granted a waiver for 3 years initially. The waiver may be

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extended for an additional 3 years if services and conditions comply with program standards.

PROGRAM COSTS AND PERSONS SERVED

The following table shows total ICF/MR expenditures and the Federal share of such expenditures since the inception of the program in FY 1973 through the estimated amount for FY 1983. The number of persons served is also shown. Currently about 80 percent of ICF/MR funds are used in public institutions and 20 percent of the funds are used in private institutions.

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TOTAL AND FEDERAL ICF/MR EXPENDITURES AND
NUMBER OF PERSONS SERVED

FISCAL YEARS	TOTAL	FEDERAL	PERSONS SERVED
	(in millions)	(in millions)	(in thousands)
1973	$ 165	$ 98	$ 29
1974	203	120	39
1975	349	204	54
1976	602	349	83
1977	871	501	101
1978	1,162	662	98
1979	1,493	844	115
1980	1,977	1,107	125
1981	2,927	1,624	196
1982	3,609	1,985	154
1983 (est.)	3,911	2,151	132 a/

a/ The estimate of persons served in FY 1983 was provided by Wayne Smith, Health Care Financing Administration.

Source: Data were provided by Ian Hill, Budget Analyst, Program Benefits Branch, Division of Budget, Office of Financial Management Services, Office of Management and Budget, Health Care Financing Administration.

In addition, under the Medicaid waiver during FY 1983, 15,600 persons were served at a total cost of $145 million, according to estimates of the Health Care Financing Administration.

III FINDINGS

The findings contained in this report regarding the conditions at ICFs/MR were determined through observation, interview, discussion and review of public documents shared by staff at the institutions. Any differences in conditions reported here are more a matter of degree than of type. The findings reported represent general patterns which emerged across institutions.

A PRIVACY

Failure to provide adequate privacy for individual residents in each of the institutions was a problem. For example, adult clients' diapers were changed in "public" areas in full view of other clients and staff. Toilets failed to provide doors or curtains for privacy. Bathing areas for clients consisted of several elevated slabs in a row without dividers for privacy.

B CLIENT ACCESS

Many buildings (both residential areas and programming areas) were locked. Clients frequently did not have access to other parts of a building or other buildings.

Client clothing was frequently locked either in individual dressers and bureaus in the sleeping areas or in a general

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clothing area. Access to clothing often required a staff person with a key.

C ADEQUACY OF CLOTHING

Staff frequently stated that they could not ensure that clients maintained their own set of clothing. Sometimes when laundry was sent out it was sorted by size upon return and distributed by size rather than by ownership.

The condition of clients' clothing was frequently poor. Ripped clothing, ill-fitting clothing, and unseasonable clothing were common.

D INCONSISTENT APPLICATION OF ICF/MR STANDARDS IN SLEEPING AREAS

There was significant variance regarding the standard number of residents per sleeping area in each institution. Most staff reported that 4 to 6 beds per room (depending on the square footage) were necessary in order to comply with ICF/MR standards. In fact several institutions had spent millions of dollars constructing buildings or redesigning buildings in order to meet the ICF/MR standard for beds per sleeping area. However, other institutions had certified sleeping areas with 35 or more clients because the federal requirement had been waived for "programmatic reasons." Explanations given for the waiver were that residents could

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not benefit from privacy and that there was not enough staff to supervise residents at night if there were fewer residents sleeping in one area.

E LIVING AREAS

Living areas of the institutions were usually barren and sterile though there was tremendous variation in the buildings (some were new and in excellent condition; other buildings were 50 or more years old and dilapidated) the barreness was consistent. There was no correlation between the newness in the building and the warmth or family like feeling of the environment. Group areas were minimally furnished with plastic chairs and sofas. Few decorative items such as pictures, plants, rugs, lamps, and tables were observed. Recreational materials such as toys, books, crayons, and records were generally not observed as being accessible to clients.

F PERSONAL POSSESSIONS

Few personal possessions were observed in bedroom areas. Usually the bedroom areas consisted of 4-6 beds and 4-6 wardrobe/dresser units. The walls were empty. There were few games, toys, records, books, pictures or personal items. Rugs were rarely observed. Mirrors in bedroom areas were rarely seen. When bedspreads were observed they were

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usually identical, indicating that residents had not made individual choices.

G MEALS

All observed meals were served on trays. Cooking was done at central cafeterias on the campuses and food either distributed to residential buildings on trays or in large containers to be dished onto trays once in the building. Some residents ate cafeteria style. The result was sometimes only one tray portion of food and one container of beverage available for each client. There were often no extra portions for replacements due to spillage or for a resident with a large appetite. There was virtually no opportunity for residents to choose their food and exert their personal preferences.

The menu was determined by the (cafeteria staff) and the same meal was offered to every resident with some variation for those on special diets. Residents ate at the time prescribed in advance by schedule.

The lack of family-like kitchen and dining facilities prevented residents from learning how to prepare their own meals, make choices about food, or learn nutritional habits and basic dining skills.

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The food sampled was bland and in some instances unidentifiable by taste. Some residents were observed being fed in a supine position. Residents who were unable to feed themselves were generally fed by staff who rotated from client to client. Observed adaptive equipment for residents with self-feeding difficulties was the exception rather than the rule. On-site observation yielded one instance of an intensive feeding skills program for clients. This program was developed under a targeted federal grant from the Administration on Developmental Disabilities.

H MEDICATION

By verbal report, medication utilization was predominantly for seizure conditions and maladaptive behavior control. Reportedly, the most comonly used medications for these conditions were melaril, valium, haldol, phenobarbital and dilantin. Although by verbal report the use of drugs for behavior management was monitored closely, observations were made of several residents sleeping during day time hours, reportedly as a side effect of medication. These residents were, of course, unable to participate in programming because of the sleeping. At one institution a report on programming for clients with behavioral problems was shared with Senate staff. The report indicated that 53 of 84 clients considered had one or more behavioral problems. Of those 53, 39 were receiving psychotropic medications while only 9 had behavioral management plans on file. There was

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little, if any, documentation to indicate that those 9 behavioral plans were being implemented. Thus, out of 53 clients with behavior problems only 16 percent were receiving behavior management programming while 74 percent were receiving medication. Contrary to federal regulations, it appears that medication is used as a substitute for behavioral programming.

I ABUSE AND NEGLECT

All institutions had developed policies and procedures to protect against and report any client abuse. However, even with the existence of such policies, all superintendents indicated that abuse of clients does occur. While some superintendents stated that abuse of clients was less than in the past, every institution had fired staff in the past year for confirmed client abuse. Staff at one institution stated that client abuse occurs in one form or another on any given day at the institution.

In two institutions unexplained pregnancies of female clients were discovered when the clients were approximatley eight months pregnant. One of the clients was nonambulatory and confined to a stretcher-like apparatus.

In two instututions locked time-out was utilized for behavior management. In one institution staff indicated that several clients were placed in locked time out each

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day. Dried blood was observed on the walls of the time out room.

J TREATMENT, HABILITATION SERVICES, AND EDUCATION

All institutions offered an educational program for their age 21 and under residents, and some type of programming for adults. The overwhelming majority of residents received their programming on the grounds of the institution. While some residents received a full day of programming, some did not. Staff observed residents who received no programming at all and residents who were in bed 24 hours per day. Staff of institutions indicated that many residents were not receiving programs to meet their individual needs. Blind clients were observed who received no mobility training; non-verbal clients were observed who reportedly received no alternative communication training; physically impaired clients were observed who received no training in feeding themselves with adaptive equipment.

Canceled classes, changes in scheduling, substitutes for absent staff were commonly observed occurences. Staff were questioned as to their awareness of the specific goals, needs, and program objectives for the clients they were working with. While some staff were clearly aware of the clients needs and implementing a program to meet those needs, some staff were not. It was not uncommon to hear statements such as "I'm really just the speech therapist,

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but I'm substituing for the person who usually runs this class."

Some pre-vocational and vocational training programs were offered in every institution. Staff frequently expressed frustration at being unable to provide appropriate vocational training/jobs for the clients. Few clients actually held jobs or worked at on-site job placements. One staff person stated that over half of the clients placed in the institution's vocational workshop could function successfully in a job setting less restrictive than a workshop, however, the appropriate alternatives were unavailable.

Observations and interviews revealed that contrary to PL 94-142, there are children under 21 receiving less than a full day of school and receiving schooling in environments which are not the least restrictive. Observation and interviews also revealed that there are adults in need of a full schedule of vocational training or job placement which is appropriate to their level of skill and independence who are not receiving such a program.

In all of the institutions, the residents who presented the most complex and profoundly handicapping conditions in need of intense therapy and training to maximize their development and prevent regression appeared to receive less

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programming compared to their higher functioning counterparts.

Others observed problems in the area of treatment and habilitative services including: children under 21 not attending school programs because of inadequate transportation or space; residents remaining in infirmaries all day with only an hour or two of programming; and decubitii (bedsores) on persons living in such units (which are the result of infrequently changed positions, proper padding devices, and/or inappropriate adaptive equipment). In one situation a little boy prone to hypothermia had not been out of bed for two years according to staff because of the lack of provision of a wheelchair which was adapted to allow the plugging in of an electric blanket.

A few exemplary programs were observed within the institutions. Most commonly these programs targeted a small number of clients (i.e., 10-20) for a specific purpose, such as visually and hearing impaired clients offered programming in a specially designed sensory stimulation environment.

IV CONCLUSIONS

1) Abuse and neglect of clients continue to persist in ICFs/MR despite a wide range of techniques and procedures utilized to attempt to eliminate this problem.

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2) In all seven facilities visited superintendents stated that there were many mentally retarded individuals in the institutions who did not belong there, but belonged in less restrictive settings. In at least one facility the superintendent judged the entire client population to be inappropriately placed there. The reason most frequently given for this situation was lack of appropriate alternatives. It is clear that a full continuum of residential settings is not available to these individuals.

3) Basic rights such as freedom of movement, privacy, and exercising choice over daily activities are abridged.

4) A full program of active treatment appropriate to meet individual needs is not yet afforded to all individuals.

5) The federal mandate (PL 94-142) requiring a free appropriate education for all handicapped children (age 3-21) has not been achieved for many institutionalized mentally retarded children and youth.

6) Problems persist with the environment in institutions. These problems include barren living areas and lack of personal possessions and furnishings.

7) Significant barriers to creating change were identified by institutional administrators and staff.

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Major barriers/impediments to change include:

o The institution must retain residents inappropriatley because necessary community alternatives do not exist.

o Appropriate community alternatives do not exist because of inadequate financing to spur development; and, existing Federal codes are prohibitive to the development of affordable available housing for clients.

o The current financing mechanism acts as a disincentive to community placement because the level of institutional revenue is tied to the size of the resident population.

o Federal policy and regulation have not kept pace with changing professional knowledge and practice as to the most benefical means of service delivery to this population. Examples include, Title XIX certification mandates requiring millions in capital spending for beds that should already be vacant or are projected to be vacant in the next few years.

o Quality assurance mechanisms are variable and inadequate. Although the governing standards and regulations for each institution are the same, in actual practice state surveying agencies varied regarding what was allowed or overlooked.

o Because the state has the authority to certify institutions for compliance to standards, there is little incentive to decertify, as such decertification would result in loss of federal funds. In essence the state would be denying itself federal funds which it would have to replace.

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o Institutions which had been investigated by the Department of Justice while certified for Medicaid reimbursement reported no knowledge of coordination between the Department of Justice and either the Department of HHS or the state certifying agency.

9) The Federal government spends a disproportionate amount of funds on large congregate care facilities for the mentally retarded, as opposed to smaller living settings. A policy of support for institutions has been established against a back-drop of conflicting legislative mandates such as education for handicapped children in the least restrictive setting.

V RECOMMENDATIONS

Despite the billions of dollars expended to run institutions for mentally retarded people, significant problems persist. The following recommendations are made:

1) Clarify federal statute, policy and regulation to expand community services for mentally retarded persons. The lack of clarity has led to a steadily escalating two-tiered system which is rapidly becoming fiscally unmanageable as states have struggled to comply with ICF/MR regulations and at the same time create community alternatives.

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2) Fiscal incentives must be provided to spur the development of community alternatives which will be required by the thousands of persons who will leave institutions.

3) Fiscal disincentives to community development should be reduced.

4) A task force should be established with representatives from the Health Care Financing Administration and other federal agencies with expertise in providing services to handicapped persons to make specific recommendations on how ICF/MR services might be changed to address the problems raised in this report and to better meet the needs of mentally retarded persons. Such a task force could be authorized as a Special Project in the Developmental Disabilities Assistance Act reauthorization Bill.

5) The mandate of the Protection and Advocacy Systems (authorized by the Developmental Disabilities Assistance Act) should be expanded to allow them access to records of clients in institutions when 1) a complaint is received on behalf of the client and 2) the client has no legal guardian other than the State. This access to records will enable active advocacy for clients' rights from an independent agency.

6) The mandate of the State Developmental Disabilities Councils and the Protection and Advocacy Systems should be

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expanded to enable them to play an oversight role in reviewing conditions in institutions. Copies of annual survey reports of ICFs/MR and plans of corrections from ICFs/MR should be made available to both the Developmental Disabilities Councils and the Protection and Advocacy Systems. Both initatives could be included in the Bill reauthorizing the Developmental Disabilities Assistance Act.

7) New positions of "Developmental Disabilities Specialist" should be established in each of the regional Health and Human Services Office. Individuals in these positions could assist in monitoring conditions in ICFs/MR, providing technical assistance, expanding coummunity placements, and placing residents in the community who are inappropriately placed in institutions.

8) A coordination mechanisim should be developed between the Department of Health and Human Services and the Department of Justice to expedite the sharing of records and information regarding ICFs/MR and to coordinate investigations.

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Senator WEICKER. It is a report which confirms conditions presented in the last hearing—a report which finds abuse and neglect, lack of programming and inappropriate placement to be major problems across the country. It is a report which calls for clarification of Federal policy and specific recommendations from HHS on how to bring services for mentally retarded persons up to acceptable standards.

It is often said that the measure of a nation's civilization is the manner in which it treats its most vulnerable citizens. Well, I am afraid that our Nation has been put to that test and has made a poor showing.

A nation that not only tolerates, but provides billions of dollars per year to support environments in which abuse and neglect are everyday occurrences can hardly pass even a minimal test of a civilized society.

We come here today to hear recommendations from the Secretary of our country's leading agency which provides services to mentally retarded persons. I have recently initiated some provisions in the fiscal year 1985 appropriations bill and the developmental disabilities bill which is going to conference, which will begin to address some of these problems.

The amount of $534,000 has been added to the HHS budget to establish 12 new positions of developmental disabilities specialists to assist these institutions in improving conditions and moving residents out who do not belong there.

The developmental disabilities bill authorizes the protection and advocacy systems to have access to records of clients in institutions. A task force is established under the direction of Secretary Heckler to provide Congress with recommendations to improve services for mentally retarded persons under title 19 of the Social Security Act.

There arrived to my attention a couple of days ago the following memorandum. On July 27, 1984, Health and Human Services sent a telegram to the ICF/MR at Mystic, CT, saying funds will be cut off in 10 days if corrections were not made. As a result of a survey made by HHS on July 11th through the 12th which confirmed 12 rapes and instances of sexual abuse and exposed the fact that mentally retarded clients were living with retarded sex offenders, some mentally ill, Health and Human Services is giving Mystic 10 days to either improve security or move offenders and increase staff or they will lose their Federal dollars.

Now, the State of Connecticut has been aware of these matters since a survey in April 1984. There are 27 residents at Mystic where 12 cases of rape and sexual abuse have been reported and confirmed. I suggest, No. 1, that obviously the State of Connecticut is in gross neglect of those who deserve our special care, but the situation in Connecticut is one that has been and is and will continue to be repeated over and over again unless action is taken by the Federal Government, and by that I do not mean negotiating.

I do mean new regulations in the sense that we requested those and they have been promised and we have not gotten them yet. But with all the concern over the politics and the parties and who is going to be elected to what, I do not see how any one of us can sit here knowing that these matters go on in our country and do not deserve our first attention.

In any event, the oversight of the committee will continue very vigorously in the months ahead and there will be further information on these matters to report at a later time.

I look forward to hearing Secretary Heckler's proposals, but before I do I would like to submit the remarks of a good friend and ranking member of this subcommittee, Senator Jennings Randolph, and also after that the statement of Senator Robert Stafford.

[The prepared statement of Senator Randolph and responses to questions submitted by Secretary Heckler follow:]

From the office of

SENATOR JENNINGS RANDOLPH

of West Virginia

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STATEMENT OF SENATOR JENNINGS RANDOLPH FOR THE HANDICAPPED SUBCOMMITTEE HEARING, "RECOMMENDATIONS TO IMPROVE SERVICES FOR MENTALLY RETARDED PERSONS." JULY 31, 1984.

I AM PLEASED, MR. CHAIRMAN, THAT YOU HAVE CALLED OUR SUBCOMMITTEE TOGETHER FOR THIS HEARING ON RECOMMENDATIONS TO IMPROVE SERVICES FOR MENTALLY RETARDED PERSONS.

I HAVE GIVEN A GREAT DEAL OF THOUGHT TO THIS SUBJECT MATTER AND WOULD LIKE AT THIS TIME TO EXPRESS THOSE THOUGHTS ON THE TOPIC WE ARE TO CONSIDER TODAY.

I HAVE HAD THE GOOD FORTUNE TO OBSERVE THE DEVELOPMENT OF PROGRAMS FOR MENTALLY RETARDED AND OTHER HANDICAPPED INDIVIDUALS FOR THE PAST 50 YEARS. I HAVE LIVED THROUGH THE PERIOD OF NEGLECT WHEN TIMES WERE DIFFICULT FOR EVERYONE AND EVEN MORE SO FOR THOSE UNFORTUNATE ENOUGH TO BE DISABLED. I LIVED THROUGH THOSE DAYS WHEN WE BELIEVED THAT INSTITUTIONAL CARE WAS THE TREATMENT OF CHOICE FOR ALL RETARDED PERSONS AND MANY PEOPLE WERE COMMITTED FOR WHOM OTHER ALTERNATIVES WOULD HAVE BEEN BETTER, HAD ALTERNATIVES BEEN AVAILABLE. I ALSO LIVED THROUGH THAT PERIOD WHEN MENTALLY RETARDED PEOPLE WERE MOVED OUT OF INSTITUTIONS AS QUICKLY AS POSSIBLE, OFTEN WITHOUT ADEQUATE PLANNING WITH THE ASSUMPTION THAT ANY COMMUNITY PLACEMENT WAS BETTER THAN ANY INSTITUTION.

EACH PASSING ERA BRINGS NEW KNOWLEDGE. EACH OF THE NEW AND BRIGHT TOMORROWS FADES INTO YESTERDAY'S MISTAKES IN THE LIGHT OF NEW IDEAS OF DAYS YET TO COME. WHAT WAS ONCE THE BEST AND ONLY ANSWER BECOMES THE PARIAH OF THE PAST. TOMORROW'S ANSWERS BECOME YESTERDAY'S MISTAKES. YET WE LEARNED FROM OUR

MISTAKES AND THE PROGRAMS OF TODAY ARE FAR SUPERIOR TO ANY WE MIGHT HAVE IMAGINED 20 YEARS AGO.

WE LIVE IN A CHANGING WORLD. WE MUST ACCEPT CHANGE AS POSITIVE AND WELCOME NEW OPPORTUNITIES; NOT SEE THEM AS AN INDICTMENT FOR ERRORS MADE IN THE PAST. IT IS NEVER AN ERROR TO DO THE BEST WE CAN, TO DO THE BEST THAT CURRENT KNOWLEDGE ALLOWS US TO DO. IT IS ONLY AN ERROR IF WE IGNORE NEW KNOWLEDGE, IF WE CONTINUE PAST PRACTICES IN THE LIGHT OF NEW KNOWLEDGE AND BETTER WAYS.

ONCE OUR GOAL WAS TO ASSURE EVERY RETARDED PERSON A PLACE IN A STATE OPERATED INSTITUTION, USUALLY AN IDYLLIC RURAL SETTING FAR FROM THE THREATENING FORCES OF SOCIETY. WE CAME CLOSE TO ACHIEVING THAT GOAL. THEN OUR GOAL WAS TO REMOVE AS MANY AS POSSIBLE FROM INSTITUTIONS AND PLACE THEM IN COMMUNITY SETTINGS AND WE HAVE ALMOST ACHIEVED THAT GOAL. WHAT IS OUR GOAL TODAY? IS IT TO KEEP PEOPLE IN SEGREGATED SETTINGS, IN SHELTERED WORKSHOPS AND ACTIVITY CENTERS FOR THE REMAINDER OF THEIR LIVES? I THINK NOT. I THINK OUR GOAL IS TO CONTINUE THE EFFORT TO REDUCE RESTRICTIONS AND TO EXPAND OPPORTUNITIES FOR RETARDED PERSONS. I THINK MOST PARENTS AND PROFESSIONALS WOULD AGREE WITH ME. I THINK THE DEPARTMENT OF EDUCATION WOULD AGREE WITH ME. I THINK THE FIELD OF REHABILITATION WOULD AGREE WITH ME.

I AM RECOMMENDING A NATIONAL GOAL TO REMOVE FROM SEGREGATED COMMUNITY FACILITIES ALL RETARDED PERSONS WHO HAVE THE CAPABILITY TO LEARN COMPETITIVE JOB SKILLS AND TO BECOME EMPLOYED. THESE PEOPLE SHOULD BE TRAINED FOR COMPETITIVE EMPLOYMENT, PLACED IN SUCH JOBS AND FOLLOWED ALONG TO ASSURE THAT PROBLEMS WHICH MIGHT DEVELOP ARE APPROPRIATELY ATTENDED TO.

I AM RECOMMENDING THAT THE DEPARTMENT OF EDUCATION DEVELOP A PLAN FOR ACHIEVING THIS GOAL. PERHAPS THE DEPARTMENT SHOULD CONSIDER A NATIONAL TASK FORCE MADE UP OF REPRESENTATIVES FROM STATE REHABILITATION AGENCIES, STATE PROGRAMS FOR THE DEVELOMENTALLY DISABLED, THE SOCIAL SECURITY ADMINISTRATION,

THE GREAT UNIVERSITIES ACROSS OUR LAND, THE U.S. DEPARTMENTS OF EDUCATION AND LABOR, EMPLOYERS AND LABOR UNIONS AND THE PARENTS OF MENTALLY RETARDED PERSONS. SUCH A TASK FORCE COULD COME UP WITH A WORKABLE PLAN TO PROVIDE THE TRAINING NEEDED TO PERMIT MENTALLY RETARDED PERSONS TO CONTINUE THEIR DEVELOPMENT IN LESS RESTRICTIVE ENVIRONMENTS, TO PARTICIPATE MORE FULLY IN OUR SOCIETY AND TO EARN THE DIGNITY THAT COMES THROUGH PAYING ONES WAY. I AM RECOMMENDING THAT THE DEPARTMENT OF EDUCATION SET GOALS AND WOULD LIKE TO SEE REALISTIC ACTION PLANS TO ACHIEVE THESE GOALS.

THE PLAN SHOULD INCLUDE WHAT IS TO HAPPEN WITH THOSE WHO CANNOT BE TRAINED FOR COMPETITIVE EMPLOYMENT. THESE ARE THE PEOPLE WHO, FOR NOW, SEEM TO REQUIRE CONTINUED CARE IN COMMUNITY REHABILITATION CENTERS. WHAT IS TO HAPPEN WITH THESE PEOPLE? WHAT ARE OUR GOALS FOR THEM? CAN THEY TOO BE EMPLOYED, ALBEIT WITHIN A SHELTERED SETTING? CAN THEY EARN MORE THAN NOW IF THEY ARE GIVEN MORE APPROPRIATE TRAINING?

I DO NOT BELIEVE THAT TODAY'S PROGRAMS ARE THE END OF THE LINE FOR MENTALLY RETARDED PEOPLE. WE ARE IN A STATE OF TRANSITION SOMEWHERE BETWEEN THE DREARY DAYS OF THE 30'S AND THE OPPORTUNITIES OF THE 21ST CENTURY. MANY OF OUR GOALS HAVE BEEN ACHIEVED BUT THE MOST EXCITING ARE THOSE GOALS NOT YET IMAGINED. THERE IS MUCH TO BE DONE BEFORE WE CAN REST.

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Senator Randolph

1. Q. How many mentally retarded individuals are currently in sheltered workshops or activity centers? How many of these do you think can be trained and successfully placed in competitive employment?

A. The Special Minimum Wage division of the Department of Labor (DOL) certifies sheltered workshops and work activity centers. Their figures show that at the close of Fiscal Year 1983, there were approximately 155,000 disabled persons employed by work activity centers, and 61,000 disabled persons employed by sheltered workshops. It is difficult to determine what percentage of these individuals are mentally retarded, as DOL's figures include workshops employing people with disabilities other than mental retardation.

Of the mentally retarded individuals in sheltered workshops or work activity centers, many are capable of competitive employment. It is a priority of my Department to increase job opportunities for disabled individuals, as demonstrated by our Employment Initiative. It is important to understand that a range of service options exists for adults with developmental disabilities. This continium of services provides for developmental services, day activity centers, sheltered workshops, training and placement programs and competitive employment. The option which is appropriate for each individual. The Employment Initiative is working with the provider and service community, as well as the private sector and other Federal agencies, in order to maximize movement through this continium and to increase competitive placements.

During the last six months, more than 30 States have placed increased priority on accomplishing this goal and almost 1,000 employers have gone on record expressing an interest in hiring workers with developmental disabilities. The National Restaurant Association has set a target of 10,000 jobs in the food service industy in 1984. We are encouraged by the progress of the Employment Initiative during the past year. As we move forward in the Decade of the Disabled, we expect to see increased movement through the continium of services and increased placement of persons with developmental disabilities into competitive employment.

Senator Randolph

2. Q. There are serious concerns that duplication of effort may result in your attempt to provide training and placement in employment for developmentally disabled individuals. How do you plan to avoid such a situation?

A. Through the Employment Initiative we have made deliberate efforts to coordinate with the efforts of other agencies that are involved in the training and placement of developmentally disabled individuals. One of our guiding principles has been that there is no need to create new programs to accomplish the goal of expanding employment opportunities for the developmentally disabled. Rather, it is necessary to assist existing programs to work together more effectively.

We have good evidence of such coordination. The Secretary of Labor, Raymond Donovan, has sent a letter to each of the Governors urging them to support the Employment Initiative by spending Job Training Partnership Act (JTPA) funds on behalf of developmentally disabled individuals. The Commissioner of the Rehabilitation Services Administration, Department of Education, also sent directives to RSA field offices supporting the Initiative. The President's Committee on Employment of the Handicapped and the President's Committee on Mental Retardation have also been full partners in our efforts. We are working collaboratively with advocacy groups and associations of facilities to assure that as we raise public awareness of the capabilities of developmentally disabled persons, those who are currently training and placing them will be able to respond by referring their clients into new work opportunities.

Senator Randolph

3. Q. It has been suggested that one of our highest priorities should be to prevent placement of your school-leavers into sheltered shops if at all possible. Does your office have any particular focus on this group?

Last year, at the request of the Assistant Secretary for Human Development Services, the Office of the Inspector General conducted a program inspection on the transition of developmentally disabled young adults from school to adult services. This service delivery assessment identified gaps in the adult service system for developmentally disabled adults. We are addressing these gaps through the Employment Initiative and by focusing discretionary funds on the issue of transition from school to community life. Our goal is to maximize integration into the community for young adults with developmental disabilities. In order to meet this goal, young adults must have available to them the full array of community options and the education system must actively participate in the transition process. We are are working closely with the Department of Education to coordinate our efforts in this area with their transition initiatives.

[The opening statement of Senator Stafford follows:]

OPENING STATEMENT OF SENATOR ROBERT T. STAFFORD

Senator STAFFORD. Let me begin by expressing my appreciation to the chairman of the subcommittee for his leadership in convening our hearing today. The staff report submitted to the Congressional Record, the legislative actions described in the developmental disabilities amendments, and the Labor/HHS appropriations bill are laudable initiatives that demonstrate the commitment of the Senate to improve services for mentally retarded persons.

The Federal Government has a longstanding commitment to caring for our Nation's mentally retarded citizens. The total cost of the intermediate care facilities for the mentally retarded exceeded $3.4 billion in fiscal year 1983. Since 1974 when the ICF/MR provisions were enacted, billions of dollars have been spent renovating residential facilities. In spite of these expenditures, conditions of abuse, lack of programming and inappropriate placement still persist. The subcommittee report confirms this. Recent visits to ICF/MR's by the Department of Health and Human Services staff confirm this. The incidents are not isolated. Problems exist nationwide.

The Congress intends to meet its commitment to mentally retarded Americans. We are here today to examine a long-term care system that has been plagued with difficulty since its inception. As a consequence, many mentally retarded people have suffered abuse, loss of dignity, and the denial of their civil liberties.

I look forward to Secretary Heckler's testimony today, and that of our other distinguished witnesses. The task before us is a complex one—it will require the collective energy of the Congress, the administration and State agencies. It is a job that won't be done until we find a way to provide long-term care and assistance to mentally retarded people without jeopardizing their health, safety, and quality of life.

Senator WEICKER. It gives me great pleasure to introduce for opening remarks a friend and colleague, Senator Thurmond. I might add that both he and his lovely wife have given great attention over the years to those of our citizens, especially those young citizens, who suffer from various disabilities.

To him, it has not been a task just as a matter of politics or Government, but a major effort in the course of his and Mrs. Thurmond's lives. So, anyway, with those opening remarks, Strom, the floor is yours.

Senator THURMOND. Thank you very much, Mr. Chairman.

It is indeed a pleasure to receive testimony this morning from our distinguished guests—Secretary Heckler, Mr. Gilhool and Mr. Melzer—in order that we may review their respective recommendations aimed at improving services for mentally retarded citizens.

I commend you, Mr. Chairman, for holding this joint hearing of the Subcommittee on the Handicapped and the Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. It is an important step in our efforts to ensure that appropriate assistance is provided to those mentally handicapped individuals in our society who are in need.

To the extent that these various recommendations are determined to be feasible, cost-effective and reasonable means of helping mentally retarded persons lead a more sound and productive life, I hope they can be promptly implemented.

It is important that citizens who are less fortunate than others are given the opportunity to overcome the obstacles which may confront them during the course of their lives. Having this opportunity is essential to their ability to develop and function to their fullest potential.

Many experts in the care of mentally handicapped persons now advocate the appropriate placement of mentally retarded citizens in the community whenever and wherever possible, thereby reducing the number of institutionalized persons.

This practice, combined with efforts to improve the adequacy of necessary institutional care, impresses me as the proper direction in which we must head. I am sure our guests will further enlighten and advise us regarding this issue as this hearing proceeds.

Accordingly, Mr. Chairman, I look forward to reading the testimony from our distinguished guests, as I have to leave to open the Senate and go to another meeting, and I am hopeful that their recommendations will be pertinent and beneficial to these important issues which face Congress and our society today.

I want to say we are very pleased to have Secretary Heckler with us, who is doing such a fine job, and I will take pleasure in reading her testimony later.

Thank you very much, Mr. Chairman, for the good work you are doing.

Senator WEICKER. Thank you, Senator Thurmond.

The first witness, then, is the Secretary of the Department of Health and Human Services. Secretary Heckler, you may proceed.

STATEMENT OF HON. MARGARET M. HECKLER, SECRETARY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY CAROLYNE DAVIS, ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION

Secretary HECKLER. Thank you, Mr. Chairman. I welcome this opportunity to appear before you today to discuss the quality of services in programs for persons with mental retardation funded by the Department of Health and Human Services.

I very much appreciate your dedication to assuring that high quality care is provided to these citizens, and I share that commitment. I have a very strong and personal interest in protecting nationwide all handicapped, and especially the mentally retarded Americans. And I must say I address the issue with a new perspective because of the depth of insight I gained in my own State of Massachusetts just last year.

Many of us remember when treatment of the mentally retarded amounted to little more than warehousing. These individuals faced harsh conditions in large, overcrowded institutions that offered little in the way of dignity, privacy, social activities or, most importantly, a chance to achieve their full potential.

Today, despite any imperfections which are present in Federal and State programs, we have come a long way. Public attention to the unique problems of these special groups has resulted in legislation designed to recognize and treat them appropriately, with dignity and as individuals.

As you are aware, Mr. Chairman, the 1972 Social Security amendments authorized medicaid funding of intermediate care facilities for the mentally retarded, known as the ICFs/MR. Medicaid is now the primary source of payment for the treatment of mentally retarded persons in residential facilities.

Since its inception, this program has grown at a rate that far exceeds any other component of the Medicaid Program. In 1973, the number of persons served in ICF's/MR was 29,000. By 1983, this population had grown to approximately 153,000.

Federal-State payments for these services accounted for 1.9 percent of total medicaid dollars in 1973. By fiscal year 1983, these payments represented 12 percent of the total. This year, the Department will funnel nearly $2.5 billion to the states to care for the ICF/MR clients—approximately $16,000 per client.

The Administration on Developmental Disabilities, established by the Developmental Disabilities Services and Facilities Construction Act of 1970, is also involved in assisting the mentally retarded.

Recognizing that services to these persons were then, and still are, continually being improved, and that services are provided by a larger number of Federal, State, local and private agencies, the major function of the developmental disabilities program is to help states in coordinating and improving their systems of services to developmentally disabled Americans.

The budget of the Administration on Developmental Disabilities for 1984 is $62 million. The impact of these funds is large, since they are used to assist States in coordinating other and much large programs, to protect the rights of developmentally disabled Americans, to train persons in providing services to developmentally dis-

abled people, and to fund research and demonstrations into better ways of providing services.

A consistent theme of our Department has been to urge greater independence and normalization for mentally retarded Americans. This year, the administration on developmental disabilities has mounted a major initiative to develop jobs in the private sector for developmentally disabled persons.

Let me move on now to the primary focus of today's hearings—the standards for ICF's/MR set by our regulations, the results of our recent series of inspections of these facilities, and our plans for improving conditions uncovered by these inspections.

First, a clarification of the Federal and State responsibilities with respect to surveillance and certification of ICF's/MR is in order.

As a prerequisite for the receipt of Federal medicaid funds, each State must certify that every facility within its borders meets Federal requirements. There are 116 Federal standards in all. Simply put, they are intended to guarantee that institutions have the capability of providing services safely and effectively; that the rights of clients are protected; that services are provided in a humane manner by qualified professionals; and that the facilities' environment is safe and clean.

The States are charged with assuring that these objectives are met. They are responsible for inspecting facilities and notifying the Department that the conditions for certification have been met.

In its oversight role, HHS has the responsibility for monitoring State performance and enforcing Federal health and safety standards. This effort was very significantly strengthened in 1980 when Congress gave us the authority to look behind State determinations. This look-behind authority allows us to send Federal survey teams to inspect facilities on a random basis, or on an individual basis if we have reason to believe a specific ICF/MR has substandard conditions.

If we find a facility does not meet Federal standards, we also have authority to terminate the facility's medicaid agreement; that is, to stop the facility from receiving reimbursement under medicaid.

This obviously is a last-resort option, since the end result might bring about displacement of a very vulnerable group of people and removal of the very funding the States need to correct their deficiencies. We feel that this drastic measure should be reserved for those instances where an attempt by the States to upgrade substandard conditions is not being made in a timely manner and when clients' health and safety requirements are in jeopardy.

As you are aware, Mr. Chairman, we recently sent on-site Federal survey teams to conduct 17 look-behind Federal inspections around the country, and have reviewed in depth the States' past survey reports of 8 others. Varying by institution, we found a broad range of problems in a number of basic areas.

For example, the majority of institutions did not meet requirements concerning provision of active treatment—a requirement added to the law to avoid creating merely another custodial type of program.

Let me explain here that the purpose of requiring active treatment services is to ensure that each client will be afforded the opportunity to gain as many independent skills as possible, as well as to prevent further physical and mental deterioration or loss of already acquired skills.

Active treatment means providing proper assessments of individual needs; individual plans of care; needed therapies, such as physical, occupational, and communication therapy, behavior modification programs, training in personal skills and social skills; as well as comprehensive protection and supervision of the clients.

In many facilities these services simply were not provided to most of the clients because of insufficient and/or poorly trained staff, inadequate physical environments, or management problems. Thus, from a services perspective, many of the clients are receiving essentially custodial, nonaggressive care, the very type of care that Congress sought to end by the ICF/MR Program.

Some were not meeting sanitation and physical environment standards. Deficiencies relating to heating, ventilation, cleanliness, and general maintenance were common. Some facilities were seriously deficient in their dispensing and/or monitoring of drugs administered to clients.

In some cases we found a very high usage of major tranquilizers, usually in the absence of effective behavior management programs designed to reduce dependency on these chemical restraints.

One facility was found to use major tranquilizers with 36 percent of the clients. We normally become alarmed at a 20 percent rate of usage; we found 36 percent. In another facility there was simply no required monitoring system available to question the excessive use of major tranquilizers. Major tranquilizers can be used inappropriately to suppress aggressive and other aberrant behavior rather than to facilitate appropriate adaptive behavior.

Many facilities also failed our requirements for food and nutrition services. Our survey teams found filthy kitchens in some, poor menu planning, inadequate preparation, and monitoring of special and modified diets, inadequate training of clients to feed themselves, and lengthy delays in serving client meals.

Some facilities were found to have life safety code—that is, fire protection—deficiencies, such as improper fire escape devices, broken or inadequate alarm systems, or improper fire walls and doors.

In one case we found large numbers of clients who were not capable of self-preservation living in residences that could not protect the clients in the event of fire. We decided this condition constituted an immediate threat to the clients' safety. We terminated the facility's medicaid agreement, which has prompted the State to take immediate action to correct this life-threatening situation.

All of the 17 facilities inspected were substandard. Nine had major health and safety deficiencies. I assure you, Mr. Chairman, that I find this situation appalling. And I find it unacceptable.

As I indicated earlier, the Department of Health and Human Services is responsible for enforcing the Federal requirement that these facilities be maintained at nationally recognized standards. I take that oversight responsibility seriously and I fully intend to

carry it out, using to full advantage the Federal Government's new look-behind authority.

At my direction, these specific actions have been taken:

In all cases where substandard conditions were noted during the recent Federal inspections, State medicaid directors have been given 30 days to respond with a firm, detailed plan for correcting these deficiencies within 180 days. Failure to deliver an acceptable plan or inadequate implementation of that plan will result in termination of the facilities from the Medicaid Program.

We have decertified one ICF/MR where there was immediate jeopardy to the health and safety of clients residing in some of the buildings. We then established a new agreement with this facility which included only those buildings which met health and safety standards.

A second facility, in Colorado, was notified of our intent to decertify it. Deficiencies were corrected, however, so that the actual program termination was avoided.

The Department has assessed a $59 million disallowance in one State, New York, for its failure during an 18-month period to comply with the life safety code and other environmental, non-life-threatening requirements.

Further initiatives have been taken. Since 9 of the 17 facilities recently inspected by our Federal survey teams were found to have serious deficiencies, a more aggressive approach is needed in monitoring States' performance and determinations.

It is clear that not all States have exercised their responsibilities to ensure that Federal health and safety standards are met. Therefore, I am proposing to strengthen the Federal surveillance function.

In conjunction with the support of the Senate Appropriations Committee with respect to services for the mentally retarded, and consistent with the committee's direction, we are planning to double our surveillance activities. We will increase the number of random surveys and the use of personnel with specific expertise in the area of mental retardation, which will greatly enhance our ability to effectively monitor the provision of services to the mentally retarded.

In the event that Federal inspections reveal deficiencies, States will be given a set period of time to give us a plan for correction, and they will be expected to adhere to that schedule.

We will carefully monitor the States' progress in moving toward complete compliance of all their facilities on a case-by-case basis, and we will apply a standard of reasonableness that fully considers client needs and States' good-faith efforts. This will be a cooperative effort with ongoing HHS-State discussions; our technical assistance will be offered to the States.

If it becomes clear that deficiencies are not being corrected within a specified time period, we will not hesitate to decertify the facility and to cut off matching funds to the State.

In no event will danger to life or limb of ICF's/MR clients be tolerated. The facility will be decertified immediately and Federal payments discontinued if such a situation is found to exist.

Finally, I have directed the Inspector General of our Department to intensify his audit activities to give particular attention to

whether Federal funds are being spent appropriately and whether clients are actually receiving the services the Federal Government is paying for.

Let me give you an example of how a persistent Federal role, combined with public demand for action, can bring results. For more than a decade, the Massachusetts State government had postponed and procrastinated in the face of serious deficiencies at five ICF/MR facilities.

In cooperation with Federal Judge Joseph Tauro, I embarked on a sustained public effort to acquaint the people of Massachusetts with the facts so that the legislature would respond by appropriating the funds necessary to bring Massachusetts into compliance with Federal standards.

Through press conferences, public statements and letters, we kept the spotlight of attention on the legislature's failure to act. Finally, I told the people of Massachusetts that unless the funds were appropriated before the legislature adjourned for the year, I would, albeit reluctantly, cut off Federal funds.

That pressure, that persistence, as well as the persistence of the court, paid off because a caring, concerned public was enlisted as allies in the effort to protect and aid the mentally retarded. This is a message I wish to convey now to all States with substandard facilities.

In summary, Mr. Chairman, in pursuit of the best interests and the needs of the client population, this Department does not intend to pay for services it has contracted for and which are not delivered or which are inferior to the established national standards.

On June 8, I alerted each Governor of each State of my intention to enforce these standards. I have every reason to believe that they will be cooperative. In the recent surveys we conducted, we were impressed by the dedication of many committed, hard-working staff in institutions and the sincere concern expressed by State officials. We fully anticipate that they will join in a concerted effort to improve services for our medicaid clients.

Mr. Chairman, you also asked that I comment on ways to foster independence of mentally retarded people and their integration into the community. I know you are very familiar with the Home and Community-Based Waivers Program, authorized by section 2176 of the Omnibus Reconciliation Act of 1981.

Under this authority, certain medicaid requirements are waived so that States can provide a variety of home and community-based services, including some services not otherwise covered under medicaid, to beneficiaries who otherwise would need institutional care.

To obtain a waiver, a State must assure that the average per capita cost of services, including the package of home and community-based services, will not be greater than the average per capita cost without a waiver.

This program, I might add, has been well received by the States; 33 States have waivers to provide services to approximately 16,500 mentally retarded individuals. Services most frequently provided under the waiver are case management, habilitation, respite care, and adult day health care. States appear to be using the waiver authority to develop alternatives to institutionalization in a careful, incremental manner.

As most of the waiver programs for mentally retarded people are still in their initial stages of operation, we do not yet have any meaningful data. However, last September HCFA initiated a 3-year evaluation study which will provide us with the insight into whether care provided in alternative settings has actually reduced the number of persons being institutionalized.

We will also be able to compare the costs of institutional and community-based care. We should be able to identify the elements of a successful program.

In addition, I mentioned that the Administration on Developmental Disabilities is sponsoring an initiative to encourage the private sector to create more jobs for the developmentally disabled persons.

I am delighted that we are beginning to recognize that even severely handicapped persons, if given the opportunity, can be employed in many situations. We would like to see, and expect to achieve, the creation of 25,000 jobs made available to the developmentally disabled in places where nonhandicapped workers are presently employed.

Mr. Chairman, in conclusion, I wish to truly applaud you and your committees for your leadership in focusing attention on this important issue. I want to reemphasize the Department's commitment to assuring high quality care for the mentally retarded wherever they reside—large institutions, small institutions, or in the community.

We stand ready to provide the States with whatever technical assistance they need to provide services in all facilities receiving Federal funds. We fully expect to achieve their cooperation.

Lacking that, however, I wish to assure you, Mr. Chairman, that I will not hesitate to exercise my authority to see that substandard facilities are decertified and Federal funds are terminated. I believe the case must be taken to the public in any and every State, if this is necessary to achieve the goal of fairness and quality care.

Mr. Chairman, we are prepared to work with you and with your committee, and we would be very pleased to hear any recommendations that you have as a result of your own inspections.

I would also like, Mr. Chairman, to ask to have Dr. Carolyne Davis, the Administrator of HCFA, who has been very personally involved in the ICF/MR inspection tours and the reimbursement issues, join me at the witness table.

Senator WEICKER. She is welcome to do so.

Secretary HECKLER. Thank you.

Senator WEICKER. Thank you very much.

Madam Secretary, your recommendation to correct these problems is to require plans of corrections and to cut off funds. Plans of corrections have been required for 10 years now; the additional authority was passed as far as the look-behind 4 years ago.

States have faced loss of funding for 10 years, so what is new about this recommendation?

Secretary HECKLER. I think that my own personal sense of commitment in terms of the utilization of the tools, as evidenced by the Massachusetts case and others, certainly will make the plan of correction an operative vehicle because I simply feel that we owe this to the client population.

I feel I am perhaps more involved with the concerns of the handicapped because it is a genuine interest of mine, but I feel very strongly that the tools that are available under the law simply cannot be used as an excuse for noncompliance.

Really, it is my function to work with the States, when that is possible and when there is a good cooperative spirit, and without that, simply utilizing the law itself to deal with the situation and require fairness for the client population.

Senator WEICKER. In your statement you say:

> In summary, Mr. Chairman, in pursuit of the best interests and the needs of the client population, this Department does not intend to pay for services it has contracted for and which are not delivered or which are inferior to the established national standards."
>
> On June 8, I alerted each governor of my intention to enforce those standards. I have every reason to believe they will be cooperative.

Why do you have every reason to believe they will be cooperative when every one of these institutions falls below the Federal standards? Why should they be cooperative now?

Secretary HECKLER. Well, Mr. Chairman, I do not believe that the Governors of the States have received special——

Senator WEICKER. Seventeen out of seventeen were substandard?

Secretary HECKLER. Yes, that is my testimony.

Senator WEICKER. Seventeen out of seventeen. All these regulations have been in place. You have been in place; your predecessor has been in place. Why do we assume that the Governors are going to be cooperative? I do not understand.

Secretary HECKLER. Well, Mr. Chairman, I have been in this post for shortly over 1 year and I have taken very, very strong action, and I intend to continue to do so. I believe that I am the first Secretary of Health and Human Services to contact these Governors to alert them to that.

Senator WEICKER. My question was not answered Madam Secretary. You made the statement, "we expect the Governors to be cooperative." Why do we expect the Governors to be cooperative?

Secretary HECKLER. The Massachusetts Governor was cooperative, and Massachusetts had dragged its feet for 10 years. And I find that while we have personally made an issue of the New York situation, the State officials appointed by the Governor have shown a sense of realization that I am very serious and firm about this and there is a cooperative mood expressed by them.

I have called other Governors when very serious situations seemed to be occurring in their States, and I must say they have been most responsive. I feel very strongly about this. In the decade of the disabled it is especially important for every public official, especially the chief executive of a State, to take the needs of the disabled, mentally retarded, or others, very seriously.

Frankly, I feel a sense that they will cooperate, and, of course, they do have a financial interest. If they lose the medicaid funding, there is a very serious financial problem that the State incurs.

Senator WEICKER. Yes, but there is a very serious impact, then, on the people that we are supposed to be serving.

Secretary HECKLER. Absolutely.

Senator WEICKER. They are the ones who will be hurt.

Secretary HECKLER. They are.

Senator WEICKER. The State and the Federal Government, if I am correct, spend $4.5 billion, Federal and State, per year, and we have not produced even one institution with no deficiencies, not one—$4.5 billion, Federal and State.

You know, what worries me a little bit is it took considerable negotiating between my committee and you, Madam Secretary. I told you that the committee was going to go out in the field, and we asked the assistance of your Department, and after much back and forth we finally had your concurrence in that assistance, which is some of the result of what we see before us here today.

Then, insofar as the followup hearing, this hearing, again it was a matter of extensive communication between this committee and your Department to have you appear before the committee.

With all the power that I can muster not only as the chairman of the Subcommittee on the Handicapped, but using my position as chairman of the appropriations subcommittee which handles your budget—with all that clout, straining and struggling, we are finally at this point here where I have your statement that we are going to enforce in-place regulations.

What bothers me is, if it takes all of this and all the clout that I hold to get to this point, what do you think is going to happen out there to the clients that you are supposed to be serving who are absolutely at the mercy of the State and the Federal Governments?

Secretary HECKLER. Mr. Chairman, I am committed to providing every service available and to supporting the needs of the clients, and I feel very strongly about it. I intend to take my responsibilities seriously.

I think that when the record is finished, you are going to be very proud of what we accomplished.

Senator WEICKER. I was told in the initial negotiations when I wanted to launch our own investigations that really you did not have that much authority to go ahead and send teams in the field.

Now, we have a statement as to the look-behind authority which was passed by the Congress in 1980--your full authority to be out there doing your investigations, as much as I have got; even more so, I might add.

Secretary HECKLER. I have exercised that authority, Mr. Chairman.

Senator WEICKER. How many persons do you have on your investigative teams right now, or in that Department which can conduct these investigations?

Secretary HECKLER. Carolyne, would you please answer?

Dr. DAVIS. Yes. We have qualified personnel in each of the regional offices that go out to do the look-behinds. This year we have been doing a 5 percent sample of all of our facilities.

Senator WEICKER. You have, what, about 2,200 facilities?

Dr. DAVIS. We have roughly 2,500 ICF's/MR and 40,000 total providers to do those look-behinds on.

Senator WEICKER. I beg your pardon? How many personnel did you say?

Dr. DAVIS. We intend to double the number of surveys next year.

Senator WEICKER. What do you have now?

Dr. DAVIS. The team will vary, sir, depending upon the expertise that is needed. But, in general, if you are going in to do a compre-

hensive survey, you need three to four individuals. It depends, of course, also, on the size of the facility. They may have to stay a week, but you need a nurse; you may need a fire safety specialist; and a generalist—somebody who has expertise in a variety of problem areas relating to the services.

Senator WEICKER. Carolyne, how many personnel do you have in the Department of HHS qualified to make the types of inspections that we are talking about? Give me the number.

Dr. DAVIS. I would say that we have about 10 to 15 qualified employees in each of our regional offices that are assigned to do look behind activities.

Senator WEICKER. And how many regional offices?

Dr. DAVIS. Ten regional offices, sir.

Senator WEICKER. So we have roughly 100 personnel to conduct these types of investigations?

Dr. DAVIS. That is correct.

Senator WEICKER. Have you, in the fiscal year 1985 budget, asked for additional personnel for this task, and if so how many?

Dr. DAVIS. I believe that in the fiscal year 1985 budget, we have an additional 12 positions—through the courtesy of the Senate Appropriations Committee—to include more individuals who have developmental disabilities backgrounds.

Senator WEICKER. How many were requested by your Department? How many additional personnel were requested by your Department?

Dr. DAVIS. I believe that we did not request additional personnel, per se, but it had been our intent to double the number of our surveys once this problem came to our attention as we began to go out and do more look-behind surveys especially in the ICF/MR area.

Senator WEICKER. Well, I accept the Secretary's statements on face value that this is a matter now that is going to be tended to vigorously. How are you going to do that with the same number of personnel?

We are talking about a hundred persons to cover some 2,200 institutions. Aside from the fact that you are going to afford your considerable talent and energies to seeing that this is vigorously pursued, I do not see how, in terms of investigation, you could do that with 100 people.

Secretary HECKLER. Mr. Chairman, we intend to target the personnel to the situations that have come to our attention and are in need of more careful scrutiny. But I really feel that the sense of firmness of my own attitude, has, hopefully, been perceived by the States and will lead to an attempt by the States to be cooperative.

Senator WEICKER. No, no. Now, Madam Secretary, the States have not done the job.

Secretary HECKLER. They have not. I agree with you.

Senator WEICKER. They have not done the job, and your own evidence shows you that.

Secretary HECKLER. I agree.

Senator WEICKER. And I think it was a darned good job that your Department did, but they have not done the job. As I said, I take your commitment absolutely; I take you at your word and I know you are going to go ahead and do the job.

You have to have people to do the job, Madam Secretary; that is all I am saying. I am tired of rhetoric of the administration in terms of what it is we are going to do. This takes bodies to go ahead and enforce the law, and there is no way around it, and bodies cost money.

I mean, I am stretched all over the place and, I will tell you, I have put together a task force out of the committees that I head that is even now out in the field. I do not have at my disposal what you have at your disposal. I am not even supposed to be doing what I am doing, but I am doing it.

Secretary HECKLER. I applaud your effort.

Senator WEICKER. Out of your own report:

> One resident was observed to be restrained naked, lying on a bed without any sheets; no toilet dividers or shower curtains were in the cottages of B Village; in review clinical autopsy findings of three deaths in the month of February 1984, the analysis of two of the cases raised questions about patient management and two cases of malnutrition on death; a resident complained on 5-10-83 that another resident sneaked into unit C-3 and had intercourse with her against her will; physical restraints, such as holding a resident's face down while straddling him, were employed by staff; one direct care staff person controlling 14 residents with behavior problems in one room; the utilization of seclusion—i.e., placing a resident alone in a locker room—because there was only one staff person on duty.

In our own report, which I am putting in the record:

> At two institutions, unexplained pregnancies of female clients were discovered when the clients were approximately eight months pregnant. One of the clients was non-ambulatory and confined to a stretcher-like apparatus.

You know, I am sorry. I mean, that is just unacceptable. It is unacceptable to me as it is unacceptable to you, as it should be unacceptable to anybody.

Secretary HECKLER. It is.

Senator WEICKER. And I think we are both well aware that the only way that we are going to get compliance is through Federal action—I mean, hooray for States' rights and the Governors. Look at my State of Connecticut. My God, here I am as chairman of this subcommittee; here is a State that had a tremendous record in the past of care of the mentally retarded under John Dempsey, and pioneered, I might add, care both at Southbury and Mansfield.

Now, Mansfield is one of the worst of the institutions as far as complaints are concerned; we have got the report on Mystic here as well. I am not about ready to go ahead and trust the States and the Governors to do the job.

The only way we are going to do the job is to have the investigations ongoing all the time so these fellows are always looking over their shoulder, never knowing when an investigator is going to be there. And when that happens, believe me, these people will receive the care they deserve, and not until.

I do not know what has been requested. Let me put it this way: I will have to take another look at the bill that we passed out of both the subcommittee and the Appropriations Full Committee.

But I would like a specific recommendation from Carolyne and from you as to what you feel is necessary in terms of investigative personnel to assure compliance with Federal regulations.

And let me tell you something; whatever you ask for, you will get, and I will bet my whole political life on it. I am serious about that now. I want you to understand that you will tell me what it is

that is needed to see that the matters that are contained in your report are attended to—and I want everybody in the room to understand that the Secretary is absolutely correct.

Her personnel unearthed these matters, as my committee unearthed these matters; it has been a joint effort. Having done that, possibly one area of disagreement might be that I am not going to put these clients at the tender mercies of the Governors. The Governors in this instance have failed miserably; not the committee, not you, not the administration, but the Governors have failed miserably.

Now, we will fail if we do not act on what we know is fact, and if you will let me know what it is that you need in the fiscal year 1985 budget just for this Department—not people who are going to roam around and do other jobs, but this job—you will get it.

I will amend that bill. I might add I am going to need your advice very fast. That bill is coming to the floor of the Senate possibly even as early as Friday. I will amend that bill on the floor and I am going to get you what you need in this area, making whatever other adjustments that are necessary in the Labor/HHS budget.

But I want it in conjunction with this so that we can do the job that you want to see done. You are a very energetic and very committed Secretary of HHS, but believe me, Margaret, you cannot do this job by yourself; you cannot.

Senator NICKLES. Mr. Chairman?

Senator WEICKER. Yes. I want to ask some questions back here. Senator Nickles?

Senator NICKLES. Thank you, Mr. Chairman.

Madam Secretary, two of the facilities that were mentioned there are Oklahoma facilities, with a large number of deficiencies on the report card. It is hard to look through and to see exactly what kinds of problems exist in these institutions. There is a deficiency in resident living areas as far as comfort, privacy, space, bedding, health, or sanitation, and so on.

I apologize for missing part of your statement. From these checks that are made, it is kind of hard to tell how bad those institutions are. I mean, it may be that you could have an investigation of all 2,200 and find 2,200 of them not passing in some standard, but they might be very good institutions. I do not know how tight these rules are.

I am aware some problems exist at these two institutions, and I would like to see that they are taken care of. I want to see that there is quality treatment for the mentally handicapped in those institutions, and I agree with you it should be done by the State. And, I agree with Senator Weicker that maybe we need to prod the States to get them to respond.

But how bad are these? Maybe you addressed that earlier in your statement. I have visited most of the institutions in the State, but I will go with this little report card in my hand now and view it with interest to see if some progress has been made or if maybe the reporters have been overzealous.

How bad do you think these nine are?

Secretary HECKLER. I think the situation is appalling; I really do. I said in my statement that I personally became very involved in the Massachusetts situation because I was familiar with the fact

that criticisms had been levied against the facilities for over a decade. Several Governors and legislatures had served during that decade, but nothing really had changed.

When I realized just how bad the facilities were after a personal tour, I utilized virtually all of the weapons available in the arsenal that we all have in public life—which you have also used in your role very, very effectively. I also had the support of Judge Tauro, a Federal judge, who took the issue very, very seriously.

After our survey of the Massachusetts institutions—which we simply found to be totally inadequate—I felt very strongly that we were being unfair to the client population if we allowed that to continue. I set a date and the State had to respond with a plan of corrective action.

The legislature had to have a special session, appropriating the funds, and I was prepared to disallow many, many millions of dollars from the State of Massachusetts unless action was taken. It was taken.

In terms of Oklahoma, similar conditions exist. In one of the facilities, less than one-half of the clients were receiving active treatment. They were really virtually in a custodial situation, which is not what we consider adequate care today.

Senator NICKLES. When you say active treatment, are you talking about educational?

Secretary HECKLER. No; just case management, concern for their needs.

Senator NICKLES. Is that Enid or Paul's Valley?

Secretary HECKLER. Pardon me?

Senator NICKLES. Was that Enid? There are two institutions.

Secretary HECKLER. Yes, this is Enid.

Senator NICKLES. Could your staff or possibly Ms. Davis supply myself with information on your findings?

Secretary HECKLER. Yes.

Senator NICKLES. Could you give us a summary of your findings at those institutions and what remedial actions you have recommended that the State take and what the timetable would be for the State to take those corrective actions, so we could follow up on it ourselves?

We have been aware that there were some, investigations going on at both, but I am not aware that we had been clued in on what they have found until today.

Secretary HECKLER. Well, we would be glad to give you the results of our survey. We found that professional services for the clients were not provided. There was no physical or occupational therapy, no psychological services. The physical environment lacked privacy and general maintenance was substandard, as was sanitation; and there were food and nutrition deficiencies, including such things as improper storage and handling of food. The reviewing of modified diets for individual patients did not exist.

These were comments and findings that the team noted in both facilities. Now, in Massachusetts I insisted that the State, after having tolerated the problem for a decade, appropriate enough funds in one session to deal with bringing the conditions in their facilities up to standards.

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The legislature in a special session appropriated $79 million just for that purpose, finally.

Senator NICKLES. Is that brick and mortar money or is that services money, or what?

Secretary HECKLER. It was everything; some of it the environment, and some of it services, especially active treatment services because, really, if we are going to have people lying in fetal positions untreated, then it is really totally unfair to the client as well as to the taxpayer who is funding the program.

I did find in the Massachusetts situation that there were many volunteers, and the staff was extremely committed. And the day that I had a public press conference on the issue, the staff standing behind me literally had tears coming down their faces because they were so supportive of what I was doing and knew that it was needed.

I just feel, frankly, that setting reasonable and fair standards for the clients, asking the States to be partners in the experience and in bringing these facilities up to date—up to conditions that are reasonable and supportive for the mentally retarded is what is needed. Also, putting the public focus on them, should the situation warrant that, does help. We do have strong tools and I do not think these conditions should be tolerated.

But I would be very happy to provide our information for you.

Senator NICKLES. The essence of the tools that you have are the survey and the possible threat or harassment of, withholding funds if you do not comply?

Secretary HECKLER. We do not intend to harass them. I mean, we will conduct the surveys in a very principled way. The intent is to serve the population and to meet the standards promulgated under Federal law.

We have very knowledgeable, professional teams who have been assembled and who have conducted these surveys. When deficiencies are found, we notify the State that they must respond with a plan of corrective action within 30 days.

Providing that this plan is sufficient to address the needs of the facilities in question, we then give the State 180 days in which to implement their plan.

Senator NICKLES. For instance, in the State of Oklahoma, is their 180-day clock now running?

Secretary HECKLER. Well, not yet because they have only been notified of the deficiencies which the survey team uncovered. They are replying and their reply is in the mail. They have 30 days in which to reply.

If their reply is adequate and provides an effective plan of action, then they have the 180 days. So they are now at the first step of the process, but I will say they are responding and I think that there is a sense of awareness that this is to be taken seriously.

Senator NICKLES. Is your investigation totally separate from that of the Department of Justice?

Secretary HECKLER. It is my understanding that it is, yes.

Senator NICKLES. We also have, I think, a concurrent investigation going on at one or two of the institutions with DOJ. Again, I have not been apprised totally from either your Department or their Department on the status, and I am interested in that.

Let me ask a question. Was your correspondence to the Governor? Was it to the director of health and human services in the State?

Secretary HECKLER. My correspondence earlier was to every Governor of every State. Based on what I had learned from the surveys, which was so appalling, it created a sense of awareness that potentially we could run into this problem in many, many States. And really it was the first responsibility of the Governor of the State to take cognizance of his own problem and to survey the situation, with full awareness that we were going to follow through and that we would take our Federal responsibility seriously.

This can mean, as you know, the disallowance of many, many millions of dollars for the State government. Therefore, they not only have the concern, hopefully, about their client population; but they also have a financial stake in not having the Federal Government withdraw substantial funding.

My first letter was sent to every Governor. Subsequently, following through on the findings of this specific set of surveys, the letters were sent by the HCFA Administrator, Dr. Davis or by the HCFA regional administrators.

Senator NICKLES. The financial relationship with medicaid with Federal and State is what percentage?

Secretary HECKLER. Fifty-fifty.

Senator NICKLES. Fifty-fifty?

Secretary HECKLER. Yes.

Senator NICKLES. In your statement, you mentioned 16,000. That is equally Federal-State?

Senator WEICKER. It is Federal.

Senator NICKLES. Is that Federal?

Senator WEICKER. It is Federal.

Secretary HECKLER. I wish to correct that. Some States get a larger than the 50-50 share if they have a lower per capita income level in the State. The 16,000 is what we have assessed as the Federal share of the individuals' needs.

Senator NICKLES. So if it is on a 50-50 basis, then the State's share would also be 16,000, so the cost for institutionalization and care would be $32,000 per year?

Secretary HECKLER. In some areas.

Senator NICKLES. You mentioned 2,200. The two institutions that you mentioned in Oklahoma are large State institutions. I would have a hard time envisioning that there are that many that large.

On the 2,200, are you talking about institutions that provide not only educational services, but also living accommodations as well?

Secretary HECKLER. Yes.

Senator NICKLES. There are actually 2,200? I guess they would range in size.

Secretary HECKLER. Very definitely. There is a very broad range of size of facility and type of living arrangement.

Senator NICKLES. In my small home town in Oklahoma, we have a school for the handicapped, and now we are expanding that into living quarters. If they had living accommodations, then I guess they would be subject to all these rules as well?

I am on the board of one of these, and we are very proud of our school.

Secretary HECKLER. Good.

Senator NICKLES. And it is primarily a school; it is not an institution, as such.

Secretary HECKLER. Senator, the issue of Federal funding relates to the medicaid eligibility of the client—well, the medicaid eligibility of a facility dealing with a large number of poor clients, so that the income level of the client population is very critical.

Senator WEICKER. If I may, if the Senator will yield, these are ICF/MR's we are talking about, not some other particular——

Secretary HECKLER. Yes. We are not talking about school facilities, in general.

Senator NICKLES. There are actually 2,200. Do you happen to have——

Senator WEICKER. It is actually about 2,500, is it not?

Dr. DAVIS. It is about 2,500.

Secretary HECKLER. Right, 2,500, and I am informed that Oklahoma has historically not chosen to certify ICF's/MR. This is a State decision as to whether or not a certain facility would be certified under this program, and the State has not chosen to do that. A number of States have taken that action, also, in the case of small facilities.

Senator NICKLES. Do you happen to have by any chance the number in Oklahoma?

Dr. DAVIS. We do not have the number in Oklahoma, sir, but in terms of the number of large facilities nationwide, there are about 75 facilities that serve over 500 clients each, and about 200 facilities serving between 100 and 300 clients. We have about 1,500 facilities that serve 15 or less clients.

But the bulk of the beds, and therefore the bulk of the dollars and the services, usually are within the larger ICF's/MR. We can get a breakdown for you in terms of Oklahoma.

Senator NICKLES. Well, I appreciate that, Dr. Davis.

Did you survey all the 75 large ones?

Dr. DAVIS. No, sir, we did not. In our Federal lookbehind, we did a sample survey.

Senator NICKLES. Are those nine institutions so bad that you think if they are not corrected pretty quick, we should cut off the funds? How bad are they? I see a bunch of checkmarks, but I am wondering when I visit what my impression will be.

Dr. DAVIS. I would say that they are serious enough that we have concerns that mean that we have asked them to respond quickly to a plan of correction. However, they do not have health and safety problems that would endanger the patients.

If there is a situation such as the Senator referred to in Mystic, we would take that more aggressive action and demand a plan of correction within 10 days, or we would decertify them.

In this case, we found that there are serious deficiencies. We believe that they need attention and we have given the States and facilities 180 days in which to do a plan of correction. We will monitor those and go back for additional site visits at that point in time.

Senator NICKLES. So maybe those are not quite as bad.

Now, Senator Weicker mentioned some very bad things, and I do not know at which State or which institution, but I think there was

a death and some rapes and sexual abuse and some very, very serious problems.

Those instances that have been raised—have steps been taken by either the local or—I could see in some cases where maybe the local groups were just ignoring these problems. Now that they have been aired by Senator Weicker's investigation and possibly your investigations, have some of the most outrageous offenses been remedied? I mean, we are not interested in 180 days for stopping those types of——

Dr. DAVIS. No; that is quite correct, sir. I sent a telegram to the State medicaid agency director on Friday, which was the day I learned of the results of this survey. The survey was done on the 11th and 12th of July, and was checked, and verified, and put into a report which reached my desk Friday morning. I took action Friday afternoon.

We are required by law to give the facilities due process time, and they have 10 days in which to make corrections or, if not, then we would move to decertify them. I think the Secretary also was extremely concerned when I notified her of this, and she may wish to speak of her actions.

Secretary HECKLER. Well, I sent a telegram to the Governor of Connecticut. I feel very strongly that this is an intolerable situation.

Senator NICKLES. Have you coordinated, or have the State officials coordinated with the Department of Justice? There is some criminal activity involved that Senator Weicker mentioned.

Has an investigation gone forward with DOJ or with the State authorities to take appropriate action in that regard?

Dr. DAVIS. We have a memorandum of understanding with the Department of Justice. Whenever we get findings that come in to us in our surveys to look like there is a problem that would be in their area, we automatically send that material to them and they then make their own determinations as to how to proceed.

So, yes, that material is forwarded to them, and I assume that they will review that and take their own action.

Senator NICKLES. Thank you both very much, and I would appreciate the information on the survey that was taken in both the Oklahoma institutions and we will follow up with you on that.

Thank you, Mr. Chairman.

Senator WEICKER. Not at all, Senator Nickles, and I will be glad to yield back some more time for whatever questions you have.

Madam Secretary, superintendents of each of the seven institutions visited by my staff stated that many of the residents should be mainstreamed into the community, and I might add I believe the same thing held true in the matters unearthed up at Mystic; that many of those persons there were felt to be capable of being mainstreamed, but they are there.

This is a response we got back from superintendents of the institutions that many clients in their institutions should not be there. The National Association of State Mental Retardation Directors has stated that thousands of residents would benefit from placements in the community. Why are these people in the institutions if they should be in the community?

Secretary HECKLER. Well, actually, the placement decisions are made by the State. This is an area over which we do not have direct authority. But I would say that there are two considerations to keep in mind.

When a client or a patient is capable of living independently, that is certainly desirable from everyone's point of view. The qualification I would have to make, though, is that we have to be as serious about being sure that the State provides alternative shelter for these people, as we are about giving those who are able to negotiate their own lives the opportunity to live freely.

I feel very strongly about mainstreaming whenever it is possible, but I also feel strongly about the need for an alternative environment. Frankly, I think that the States have been lax in this as well.

Senator WEICKER. I would appreciate receiving from you or Carolyn recommendations as to what authority you would need in this area to get the States moving these people out of the institutions. I agree with you; you cannot put them out if there is no place to go.

But I am of the opinion that possibly the law is deficient in that area as to the authority it gives to you to see that that is effective. Since there is press present, I think it might be just a good time to point out that regardless of what the common conception is—and I might add I had it at one point myself until I had hearings in Hartford, CT, where I was proven wrong in my thinking.

Never mind the humanity that is involved in the situation; it is far less expensive to have the person mainstreamed than it is to have them institutionalized. So if anybody thinks that warehousing is something that is cheap as compared to the alternative of mainstreaming, it is not; it is the most expensive care that you can give, which leads me to the second point—$16,000 is the Federal share per patient in this country—$16,000.

Secretary HECKLER. That is right.

Senator WEICKER. Now, if you double that, it is $32,000 per patient, and I would ask anybody what they would expect for that amount of money if that money were going to their child. I do not think the tuition at Yale or Harvard is that high.

Secretary HECKLER. Right, I would agree with you.

Senator WEICKER. Here you have $32,000, and I suppose I am not in charge of the State share, but let us take the $16,000 that is our responsibility. It is a big slug of dough, and it was intended by the Congress and the administration to see that $16,000 go to that individual. These clients are deserving of more than slabs of concrete and open showers and toilets and rape and unprofessional personnel for $16,000 per year.

If you do not want to put it on a humanitarian basis, let us talk about money. It is not a question that we are trying to do something on a pittance around here.

I have no further comments. it is my understanding from talking to staff that the Appropriations Subcommittee added 12 personnel for the Department of HHS vis-a-vis monitoring of this situation.

Secretary HECKLER. Right.

Senator WEICKER. That is not what I am talking about. I think that is very much necessary. I am talking about additional person-

nel which would be required in the regional offices to complement the 12 additional that the committee put in.

I think that your advocacy can carry the ball within the administration, but I am more than glad to work as chairman of the Appropriations Committee with the administration to see that this matter is properly handled on the floor. It should be handled on the floor.

Now, as to the matter of harassment, I will not use that word, but I will say this: I intend to stay, just as you have indicated, all over the backs of these people until they get their act together.

It is not a matter that anybody is looking for more things to do. I think what we are looking for is less things to do, but certainly that the law is upheld. I feel that the best way to do that is just to have a constant monitoring process.

Right now, I assume that they feel you do not have enough personnel—I do not have enough personnel, that is for sure—so they play the odds that "we will get away with it, and if we can get away with it for 10 years, fine; we are nailed in the 11th year. We have gone ahead and done the job monetarily; we are ahead of the game."

I want them to understand that they can expect that somebody is going to be around every year and that they ought to go ahead and keep the game honest. I really think that by far and away, the most accurate test of our effectiveness insofar as how we use our power is how we use it in this instance. If we can do it here, then we are doing the job we are elected to do.

So, if you would, get the figures to me prior to Thursday. The staff director informs me that we do need the figures by then. It now would appear that we are going to the floor on Friday, and in order to go ahead and prepare for that, I would greatly appreciate your providing the information promptly.

Secretary HECKLER. We will provide it for you, Mr. Chairman.

Senator WEICKER. Maybe Carolyne could be in touch with Claudia Ingram, who is the staff director of Labor/HHS.

I want to commend you and your staff for tackling this situation. It is not a pleasant thing in an election year, but the alternative is we all wait until the election blows over, and if we wait until then, everybody who is in these institutions will get subjected to the conditions that you have described and my staff has described to me, and I do not think that is right.

Regardless of where it falls, the time to do the job is right now. I might add that I am dispatching staff to Connecticut myself. Any way that we can work on that, we will be of assistance to you.

It is not easy to express the lack of pride that I have in my own State on this matter. I am sure it was not easy for you to express the same thing in your State of Massachusetts.

Secretary HECKLER. Right.

Senator WEICKER. But I am not going to defend anything like this for the State of Connecticut, and neither are you for Massachusetts.

Secretary HECKLER. I am not.

Senator WEICKER. And neither should anybody around here.

I thank you for the help that you have given to the committee. I look forward to working with you on correcting the situation, and

hopefully when we meet again we will have the positive results of the report.

Any further statement by you, Madam Secretary, would be welcome.

Secretary HECKLER. Thank you, Mr. Chairman. I think that we are in agreement in terms of what the goals have to be, and I think that we are very serious about our problems. We figured out that in New York, if we had put some of the patients in some of the most expensive hotels, they would have gotten better treatment and it would have cost less.

Senator WEICKER. No question about it. Just before you leave, Senator Stafford has arrived. Bob, is there anything that you would like to comment on to the Secretary? I have finished with questions, but we would be delighted to have you contribute.

Senator STAFFORD. Thank you, Mr. Chairman. My only comment will be to welcome the Secretary, and to give my apologies for the fact that the Committee on Environment and Public Works this morning is meeting on Superfund. Since I am chairman of that committee, I have had to be there until this moment.

I have a few questions I would like to submit in writing to the Secretary, if I may, for response at your earliest convenience.

Secretary HECKLER. We would be happy to respond.

[Responses of Secretary Heckler to questions submitted by Senator Weicker follow:]

Senator Weicker

1. Q. In 1981, Congress amended the Social Security Act with the "Community Waiver" Provision, so mentally retarded people could be served in the community instead of in institutions.

Please provide an update on the implementation of this program.

A. The chart below provides you with updated information, as of August 20, 1984.

MEDICAID WAIVER FACT SHEET
HOME AND COMMUNITY-BASED SERVICES
Status of all Requests

	Received	Pending	Approved	Withdrawn	Disapproved
Total Waivers	129	38	76	7	8
Total States Submitting Request	47				
Total States With Approved Waivers	44				
Total Model Waivers	21	10	11		

STATUS OF MR/DD REQUESTS ONLY

	Received	Pending	Approved	Withdrawn	Disapproved
Total Waivers	63	18	39	2	4
Total States Submitting Request	36				
Total States With Approved Waivers	33				
Total Model Waivers	12	5	7		

Senator Weicker

2. Q. The legislative history makes it clear that Congress intended, through the waiver, to remove at least some of the institutional bias inherent in the Medicaid system.

As a matter of HHS policy, do you view the Medicaid waiver as a way to reduce reliance on institutional services or as a method of health cost containment?

A. Clearly, the home and community-based services waiver program helps the States to deinstitutionalize Medicaid recipients who can be served in the community at no additional cost to the Medicaid program. You should be aware that the law specifically states that the cost of services provided in the community are not to exceed the cost of the institutional services.

3. Q. States such as Vermont are soon going to be coming to HHS for renewal of their community waiver program. It is my understanding that final regulations for this program have never been approved. This is causing some concern to the states involved.

When do you expect these regulations to be finalized?

A. Dr. Davis, HCFA Administrator, informs me that the regulations are in the final clearance process within HCFA and will soon be in my office for review.

Senator Weicker

4. Q. Why are people in institutions if they should be in the community?

A. The reasons most commonly given to us as to why individuals remain in institutions when professionals agree community placement is preferable include:

- o lack of available community alternatives including adult foster care, supervised apartments, other non-Medicaid reimbursable settings as well as small (15 beds or less) ICFs/MR;
- o unwillingness of family members to allow community placements; and
- o community resistance to additional placements, especially in the context of other groups seeking community placements (e.g., persons with chronic mental illness, persons in prison release programs, etc.).

Q. Does current law or HHS policy limit Federal ability to see that mentally retarded people who should be placed in the community are in fact, placed in the community?

A. The Medicaid statute requires that payment be based on the care of individuals certified for a given level of care such as SNF, ICF or ICF/MR, not whether a placement in a larger public institution or a smaller community based facility is more desirable than another. Thus, if a client is eligible for the ICF/MR level of care, we have no authority to say which specific setting is the most appropriate. The monitoring of level of care and placement decisions under Medicaid rests solely with the State. Our authority to monitor State utilization control programs is largely procedural.

Q. What recommendations do you have to see that these individuals are moved into the community?

A. Individual placement decisions are best left to the States. We believe greater Federal activity in this area would be unworkable and would require Federal officials to work directly in each State with thousands of cases in order to exercise whatever additional authority might be provided.

Senator Weicker

5. Q. Does the State survey and certification authority in the ICF/MR program constitute a "substantial conflict of interest?"

A. We would certainly agree that States' authority to survey and certify their own institutions provides the opportunity for a conflict of interest, especially since the possibility of a loss of Medicaid funds can result in serious problems for States. States, in our view, seek to ensure that the survey agency findings are respected and responded to. However, it is obvious that States have no incentive to take away their own certifications.

As a check for such situations though, we can exercise our "look-behind" authority and conduct reviews with our own Federal survey teams. As you are aware, we have recently done so in a number of instances.

Q. What do results of recent Federal surveys say about reliability of State findings for certification?

A. Overall, with a few exceptions, we found our survey results to be essentially the same as prior State findings. There were some exceptions where State surveyors found few problems and we found serious problems, but, generally, our problem in the past has not been the accuracy or the quality of State findings.

6. Q. The current HHS regulations for the ICF/MR program are 10 years old. For two years now HHS has been working on new regulations. At my appropriations hearing in the spring you stated that those regulations would be issued very shortly. What is holding up these regulations?

A. We have prepared new draft standards for ICFs/MR that reflect the significant progress in treatment practices that has taken place over the past decade.

To assure that the draft standards meet the needs of the developmentally disabled, while not imposing undue regulatory burdens on facilities, the draft standards have undergone substantial review and comment within HCFA. This process has been necessary so that the regulations, especially those sections dealing with active treatment, will be enforceable and will in fact result in appropriate placement of clients and appropriate treatment. We are concerned that the updated regulations be structured in such a way that we can determine the capacity of each facility to furnish appropriate treatment and quality services.

We are unable to predict precisely when our completed review will enable us to publish a Notice of Proposed Rulemaking, but we are sensitive to the concerns of the Subcommittee on the Handicapped of the Senate Appropriations Committee, as well as the needs of the professionals who serve this client population.

7. Q. How often do you and Mr. Reynolds (Head of the Civil Rights Division of the Department of Justice) meet to coordinate efforts to investigate problems of abuse and neglect in institutions?

A. These meetings are carried out by staff offices below the Office of the Secretary. We have had several meetings between our Office of General Counsel and the Department of Justice (DOJ) staff to discuss the coordination of information by HCFA with DOJ.

Q. How many cases of abuse and neglect have you referred to the Department of Justice?

A. From January 1 to August 22, 1984, we have sent information concerning facilities on 24 occasions. From July 1, 1983 through December 31, 1983 we sent facility information on 34 occasions.

Q. When was the last time you made a referral to the Department of Justice?

A. As noted above, we have an ongoing relationship with DOJ in the provision of information, with 24 such instances within the dates mentioned above. I think this connotes an active relationship between us and the DOJ in this area.

Q. What procedure do you have in place to ensure a rapid response to requests from the DOJ regarding investigations of institutions?

A. The DOJ contacts our Office of General Counsel. On the same day we then notify the appropriate regional office attorney. The regional attorney obtains the information from the HCFA regional office and reviews it to be sure that it contains no information which would violate confidentiality and privacy requirements. The information is then forwarded to our central office Office of General Counsel, which then sends it to DOJ.

Senator Weicker

8. Q. An April,1982 study conducted by GAO concluded that current ICF/MR regulations "do not define when a facility's capacity to give adequate care is seriously limited or provide adequate guidelines as to when a State should deny certification because of lack of active treatment."

GAO recommended that you establish standards which MUST be met (and cannot be waived) in order for a facility to be certified.

Why hasn't this been done?

A. We believe that the draft proposed standards for ICFs/MR will enable us to identify those facilities that have the capacity to furnish adequate care and set out clearly the requirements each facility must meet in order to participate in Medicaid's ICF/MR program. Our careful scrutiny of the updated proposed regulations has been focused in large part on assuring our ability to determine whether the provision of adequate care is actually taking place.

There is a new section on active treatment that will greatly facilitate a State's determination of whether clients are receiving active treatment. All standards must be met for a facility to be certified, unless it has an acceptable plan of correction for deficiencies that do not threaten the health and safety of its clients. This policy also applies to existing standards.

9. Q. At what point do conditions (e.g., repeat deficiencies) become unacceptable?

A. Except as allowed in our regulations (e.g., if a standard was met during the year, but then was "out" at survey because a staff person resigned, etc.), repeat deficiencies are never acceptable. Our standards require that regulations be met. In practice, we recognize that repeat deficiencies have occurred, and it is our intention through increased Federal monitoring of State survey practices that repeat deficiencies are not allowed and that appropriate actions are taken when they do.

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Senator STAFFORD. Thank you, Mr. Chairman.

Senator WEICKER. Thank you, Senator Stafford.

Thank you very much, Madam Secretary.

Secretary HECKLER. Thank you, Mr. Chairman.

Senator WEICKER. The next witnesses will be Mr. Thomas Gilhool, chief counsel, Public Interest Law Center of Philadelphia, and Ronald Melzer, the director of mental retardation programs of the Vermont Department of Mental Health.

Senator STAFFORD. If I can introduce him, then I am going to have to leave.

Senator WEICKER. Absolutely right; that is exactly what you are going to do.

Senator STAFFORD. Mr. Chairman, as soon as the committee's visitors have quieted down, it will be my privilege to have the opportunity to introduce Dr. Ronald Melzer, director of community mental retardation programs in the State of Vermont.

I am glad you are here, Doctor.

Dr. MELZER. Thank you, Senator.

Senator STAFFORD. Dr. Melzer has served in that capacity since 1975. He has responsibility for coordinating all placements from the institutions in Vermont into community-based programs, and for supervising mentally retarded persons who are under custody of the commissioner of mental health.

Dr. Melzer is an active member of the National Association of State Mental Retardation Program Directors, and has served as a consultant on the uses of medicaid in residential and day services for mentally retarded people around the country. He brings to this hearing vast experience in the field and an impressive record of accomplishment in Vermont.

It has been under his able leadership that Vermont has developed its reputation as a leader in making community care alternatives available to mentally retarded people. I look forward to hearing his testimony today, and thank him for taking the time and the trouble to prepare for and appear before these subcommittees this morning.

I do have to apologize to the chairman and to you, Doctor, for the fact that I am overdue for a meeting with the Senate majority leader, Senator Baker, in the Capitol, so I am going to have to leave rather precipitously. But I will read your remarks very carefully.

Dr. MELZER. Thank you, Senator.

Senator WEICKER. Thank you very much, Senator Stafford. Why do we not let Dr. Melzer start off? I might add that your statements in their entirety will be included in the record. I think, really, it is so rare that we have opportunities to dialog with two experts in the field that possibly you could synopsize those so that we can have a little back-and-forth here and some questions.

Dr. Melzer?

STATEMENT OF RONALD MELZER, DIRECTOR, COMMUNITY MENTAL RETARDATION PROGRAMS, VERMONT DEPARTMENT OF MENTAL HEALTH; AND THOMAS K. GILHOOL, CHIEF COUNSEL, PUBLIC INTEREST LAW CENTER OF PHILADELPHIA

Dr. MELZER. Thank you, Mr. Chairman.

I trust we would all agree that abuse and neglect are a reality in the lives of many mentally retarded Americans today. That such conditions exist even in facilities which are regularly visited by State and Federal officials, I think, has been adequately documented in the proceedings of the subcommittee.

But as we look to the elimination of these conditions, we must not lose sight of the fact that many mentally retarded persons who could be living in the community right now are still in large, segregated facilities, and many others are in great danger of being needlessly institutionalized.

While mentally retarded persons may have needs for specialized training and assistance, they share with us all the basic needs for nurturance and continuity that are provided by the nuclear family.

We also know that even persons with the most severe handicaps can be cared for in their own homes and in other community settings when appropriate services and supports are in place.

The Congress apparently recognized the importance and desirability of offering alternatives to institutional care when it enacted the medicaid home and community-based waiver authority.

Just as the ICF/MR legislation spoke to the need for improving conditions in facilities for mentally retarded persons, the waiver represented a significant departure from the longstanding institutional bias within the medicaid program.

Vermont, like many other States, enthusiastically welcomed this new opportunity to provide alternatives to institutional care. Since July 1982, we have moved 104 persons from our State institutions into the community, and have provided services for 50 others who would have required ICF/MR level care.

I know that by Washington standards, these numbers may not sound that impressive, but to put it in the Vermont context, that represents a reduction of one-third of the medicaid-funded long-term care beds in the mental retardation system in Vermont.

Many of those who were moved were persons with severe handicaps for whom community living was not even considered feasible less than a decade ago. Nonetheless, they have thrived in their new settings and the average cost of their care has been reduced by almost $20,000 per year.

On March 31, 1985, Vermont's initial 3-year waiver will end. As we look to the continuation of the program, we are greatly concerned that final regulations have never been promulgated and that the procedure for renewal is, as yet, unpublished.

Furthermore, as we speak to our colleagues in other States, it appears that there is a move underway to greatly reduce, if not totally eliminate, the waiver program. In its most recent dealings with States who are seeking waivers, the Health Care Financing Administration, in apparent collaboration with the Office of Management and Budget, has imposed requirements which seem to extend way beyond the provisions of the original law.

For example, while the Congress said that States must demonstrate that the total cost of medical assistance would not be greater under a waiver, the administration now says that expenditures for waiver recipients must include outlays for SSI, AFDC and food stamps.

The Congress indicated that States should not determine the feasibility of providing community-based care on the basis of whether or not such arrangements would produce short-term savings, but the administration now insists that waiver programs produce immediate savings.

The Congress envisioned that those who were at risk of institutionalization, as well as those already in long-term care, could benefit from the waiver. Now, however, States are finding it increasingly difficult to include this at-risk population in their waiver program.

If the full potential of the waiver is ever to be realized, some changes must be made. First, it is essential that final regulations be promulgated, and that those regulations be consistent with the provisions and intent of the law. Until that happens, States cannot know for certain by what standards they will ultimately be judged.

Second, serious consideration should be given to making waiver services permanent components of the medicaid law. At the same time, the number and types of those services which can be offered as alternatives to institutional care should be expanded.

For example, the provision of prevocational services to those who would otherwise be ineligible for training under the generic vocational rehabilitation program could greatly contribute to the reduction of perpetual and total dependency.

Finally, Congress should reiterate that the waiver was not intended exclusively as a cost containment measure, but was designed to reduce our reliance on institutional care. If we truly believe that mentally retarded persons should be maintained in their own home and community, then we need to commit the necessary resources.

By so doing, I am convinced that we can look forward to a service system of the future that is far more humane and cost-effective than the system which has been the focus of these hearings.

Thank you, Senator.

[The prepared statement of Dr. Melzer and responses to questions submitted by Senator Weicker follow:]

PREPARED STATEMENT OF RONALD MELZER,
DIRECTOR, COMMUNITY MENTAL RETARDATION PROGRAMS,
VERMONT DEPARTMENT OF MENTAL HEALTH

Mr. Chairman and members of the subcommittee, it is a great personal pleasure to appear before you today.

By way of introduction, I have served as Vermont's Director of Community Mental Rotardation Programs for nine years, during which time, I have been responsible for overseeing the development of services for approximately 1,000 mentally retarded citizens. In addition, I have provided consultation and technical assistance to more than a dozen states in the use of Medicaid funding for community-based services. Most recently, I was appointed by the United States District Court in Connecticut to monitor that state's compliance with a consent decree involving the Mansfield Training School.

I trust we would all agree that abuse and neglect continue to be a reality in the lives of many Americans who are mentally retarded. That such practices exist even in certified facilities which are regularly inspected by state and federal officials has been repeatedly documented in the proceedings of this subcommittee. As we look to the elimination of these conditions, however, we must not lose sight of the fact that many persons who could be living in the community right now are still in large, segregated facilities, and others are at great risk of being needlessly institutionalized.

While mentally retarded and other dependent persons may require specialized training and assistance, they share with us all a basic need for nurtuance and continuity that is traditionally provided by

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the nuclear family. We also know that even those with the most severe handicaps can live in their own homes or other community settings when appropriate services and supports are available.

The Congress apparently recognized the importance and desirability of offering alternatives to institutional care when it enacted the Medicaid home and community-based waiver authority. Just as the ICF/MR legislation of 1974 spoke to the need of improving conditions in facilities for mentally retarded persons, the waiver represented a significant departure from the long-standing institutional bias within the Medicaid program.

Vermont, like many other states, enthusiastically welcomed the opportunity to increase the availability of alternatives to institutional care. Since July of 1982, we have moved 104 mentally retarded persons from state institutions into the community, and have provided services to 50 more who would have otherwise required ICF/MR care. In so doing, Vermont has reduced by one-third the number of Medicaid-funded long term care beds in its mental retardation system. Many of those moved were persons with severe handicaps and long periods of institutionalization for whom community living was not even considered feasible less than a decade ago. Nonetheless, they have thrived in their new settings, while the cost of their care and habilitation has been reduced by an average of almost $20,000 per year.

On March 31, 1985, Vermont's initial three year waiver will end. As we look to continuation of the program, we are concerned that final regulations have never been promulgated and that the procedure for renewal is, as yet, unpublished. Furthermore, as we speak to colleagues in other states, it appears that there is an effort underway to drastically

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reduce, if not totally eliminate, the waiver program.

In its most recent dealings with states who are seeking waivers, the Health Care Financing Administration, in collaboration with the Office of Management and Budget, has imposed requirements which seem to extend far beyond the provisions of the law. For example, while the Congress said that states must demonstrate that the total cost of medical assistance would not be greater under a waiver, the Administration now says that expenditures for waiver recipients must include outlays for Supplemental Security Income, Aid to Families with Dependent Children, and Food Stamps. The Congress noted that states should not determine the feasibility of providing community-based care on the basis of whether or not such arrangements would produce short term cost savings; but the Administration now insists that waiver programs produce immediate savings. The Congress envisioned that those who were at risk of institutionalization, as well as those already in long term care, could benefit from the waiver. Now, however, states are finding it increasingly difficult to include the at-risk population in their waiver programs. If the potential benefits of the waiver legislation are ever to be realized, some changes must be made.

First, it is essential that final regulations, which are consistent with the provisions and intent of the law, be promulgated. Until this happens, states will not have the benefit of knowing for certain by which standards they are to be judged.

Secondly, serious consideration should be given to making waiver services permanent components of the Medicaid law. At the same time, the number and types of services which can be offered as alternatives to institutional care should be expanded. For example, the provision

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of prevocational services to those who are not eligible for training under the generic vocational rehabilitation program could significantly contribute to a reduction of perpetual and total dependency.

Finally, the Congress should reiterate that the waiver was not intended exclusively as a cost containment measure, but was designed to reduce our reliance on institutional care. If we truly believe that mentally retarded and other dependent persons should be maintained in their homes and communities, then we must be prepared to commit the necessary resources. By so doing, we can look forward to a service system of the future which will be far more humane and cost-effective than the one which has been the focus of these hearings.

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Commissioner's Office
Community Mental Health Programs
Community Mental Retardation Programs
Vermont State Hospital
Brandon Training School

STATE OF VERMONT
DEPARTMENT OF MENTAL HEALTH
Agency of Human Services

MAILING ADDRESS:
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Center Building
103 South Main Street
Waterbury, Vermont 05676

September 14, 1984

Honorable Lowell Weicker, Jr.
Chairman
Subcommittee on the Handicapped
Committee on Labor and Human Resources
United States Senate
Washington, DC 20510

Dear Senator Weicker:

I very much appreciated the opportunity to participate in the hearing conducted by the Subcommittee on July 31, 1984.

Following, are my responses to additional questions posed by the Subcommittee:

(1) UNDER THE WAIVER, VERMONT APPEARS TO BE MOVING TOWARD MAKING RESIDENTIAL ALTERNATIVES AVAILABLE TO ALL MENTALLY RETARDED PEOPLE WHO WANT TO LIVE IN THE COMMUNITY.

WHAT PREVENTS OTHER STATES FROM DOING THE SAME?

A number of factors have contributed to under-utilization of the waiver, not the least of which is a reluctance on the part of some states to initiate a program whose long term stability has been questionable from the outset. Since waivers under the Medicaid program have traditionally been associated with time-limited research and demonstration projects, it is not surprising to find states adopting a "wait and see" attitude.

Another factor is the difficulty of obtaining approval for waivers whose primary focus is the prevention of institutionalization. The Department of Health and Human Services (HHS) continues to ignore the fact that a majority of mentally retarded persons -- including those with the most severe handicaps -- have always lived at home; and apparently concludes that all or most of those who are eligible for ICF/MR level care are already institutionalized. States, in turn, are precluded from using the waiver for the at-risk population unless they can demonstrate that a sufficient number of Medicaid-funded beds could be made available to accommodate these individuals. Systematic as this approach may seem, there is no demonstrated correlation between a state's supply of long term care beds and persons in need of such care. To illustrate, in 1982, the number of

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beds in large ICF/MR's per 100,000 persons in a state's general population ranged nationally from 9 to 110. If institutional beds were truly an index of the need for ICF/MR care, the implication would be that some states have an incidence of significant mental retardation which is more than ten times greater than that of others. This degree of variance is not supported by any evidence of which I am aware.

Additionally, the lack of a clear federal policy on what constitutes an approvable waiver has resulted in long delays in the review of applications, and has produced determinations by HHS that are often inconsistent and sometimes contradictory.

(2) VERMONT WILL BE PREPARING FOR THE RENEWAL OF ITS COMMUNITY WAIVER WITH HHS IN THE NEAR FUTURE.

DO YOU ANTICIPATE ANY DIFFICULTY SECURING THIS RENEWAL IN LIGHT OF THE NEW ROLE OMB IS PLAYING IN THE PROCESS?

Based on recent experiences of other states, it is difficult to imagine otherwise.

Even before the active involvement of OMB in the review process, officials of HHS were stating that some waivers approved shortly after passage of the enabling legislation would not have been acceptable if submitted a year later. Despite this indication that the rules of the game had indeed changed, no federal communication was ever issued advising the states of the criteria used for review of applications.

With the entry of OMB, a conflict has evidently developed regarding the locus of ultimate authority to approve or deny waivers, as well as the criteria by which applications should be judged. A notable example is the question of which costs are to be considered in the calculation of the regulatory formula for estimating waiver expenditures. At first, states were required to include only long term care expenditures in their comparison. Then, some months ago, HHS began to advise states (on a one-by-one basis as they made application) that estimated expenditures for SSI, Food Stamps, AFDC, as well as other medical assistance payments, would need to be included in the formula. Now we are being advised that only Medicaid costs will be used in evaluating a state's application.

A further example of the lack of clarity in review criteria involves methods by which HHS determines the validity of a state's estimate of beneficiaries at risk of institutionalization. Although we have heard that greater attention will be given to indicators of future long term care bed supply and to assessment instruments used by states in determining a beneficiary's eligibility, the precise criteria that HHS intends to use are, as yet, unpublished.

Until these issues are clarified, any state, including Vermont, that seeks initial or ongoing approval for a home and community-based services waiver has a legitimate cause for concern.

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(3) I SHARE YOUR VIEW THAT THE PRIMARY INTENT OF CONGRESS IN ALLOWING FOR THE COMMUNITY-BASED WAIVER UNDER MEDICAID WAS TO REMOVE THE INSTITUTIONAL BIAS INHERENT TO THE FLOW OF FEDERAL DOLLARS.

HAS THIS LEGISLATION ACCOMPLISHED THAT GOAL?

To this point, I think the answer must be that the promise of the legislation has far exceeded the reality of its implementation. Certainly, that the waiver allows states to cover a new array of medical and nonmedical services under its Medicaid program is a significant departure from long-standing practice. However, the fact that a state needs specific approval to offer home and community-based services while it can maintain or even increase the level of its institutional services without federal review, is evidence that the traditional bias still exists.

At present, a state can unilaterally add any number of ICF/MR beds for new clients with the certainty of receiving federal reimbursement so long as it complies with established regulations. But if it chooses to serve those same individuals in their home or other community settings, that state must first convince HHS that its needs are valid. Even then, the state can look forward to no more than three years of funding before submitting again to the approval process.

Under these circumstances, it should not be surprising to see states again relying on the more predictable options of institutional care, especially in the case of new clients who require out-of-home placement and cannot be readily served through the waiver.

(4) DR. MELZER, SECRETARY HECKLER STATED IN HER TESTIMONY THAT COST SAVINGS INFORMATION FOR COMMUNITY VS. INSTITUTIONAL CARE IS NOT YET AVAILABLE.

DO YOU HAVE INFORMATION ABOUT COST SAVINGS IN VERMONT UNDER THE WAIVER PROGRAM?

For all mentally retarded beneficiaries now receiving waiver services in Vermont, the mean annual expenditure is $21,100. By comparison, the current Medicaid rate is $37,900 (on average) in Vermont's community ICF/MR's; $49,600 at the Brandon Training School; and, $56,000 at the Vermont State Hospital, where 24 individuals lived immediately prior to going on the waiver.

If expenditures for SSI and other medical assistance payments (e.g., physicians, hospitals, drugs, etc.) are added, it is still inconceivable that the total cost for waiver recipients would equal the cost of institutional care.

In Vermont, we have never justified community-based services solely on the basis of cost savings. Instead, we have focused on the programmatic benefits of small, home-like environments, as well as the rights of handicapped persons to receive services in settings which are least restrictive of personal freedom. Based on our experience, though, we can conclude that on a system-wide basis, community services are less costly than institutional care. Just as significant, are the observations that clients make more progress in

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community-based programs, have greater opportunities to utilize generic community resources and services along with their nonhandicapped peers, and are generally able to establish and maintain more normative lifestyles. Hopefully, at some point HHS will recognize that cost-effectiveness is not simply defined by dollar outlays, but must include some measures of benefit to the client.

(5) YOU MENTIONED IN YOUR TESTIMONY THE NEED FOR HHS TO PROMULGATE FINAL REGULATIONS FOR COMMUNITY CARE WAIVERS.

WHAT DO YOU HOPE WILL BE ACCOMPLISHED UNDER A REVISED REGULATORY SYSTEM?

Vermont, like other states, has made substantial resource commitments based on HHS's original interpretations of the waiver legislation. Given the speed with which the waiver regulations were first issued, it was understandable that certain issues might initially remain unresolved in the interest of getting programs under way. The earliest applicants, for example, were required to make an assurance that they would provide data to the Secretary according to a format which was still unspecified.

With the passage of time, however, states have become increasingly concerned that significant policy questions continue to go unanswered. In an attempt to obtain clarification on some of these issues, the National Association of State Mental Retardation Programs Directors wrote to then Secretary Richard Schweiker on July 2, 1982, asking, among other things: how HHS planned to actually determine whether a state was in compliance with the regulations; how disputed claims would be handled; and, how HHS intended to disseminate information about policy decisions that were made subsequent to issuance of the regulations. The reponse, dated November 23, 1982, indicated that soon-to-be issued final regulations would address all of the Association's concerns. Not only are those final regulations still unpublished, but speculation continues to grow about the nature and extent of modifications that will be made to the original rules.

From the Administration's perspective, it is obviously advantageous to continue operation without the burden of regulations that clearly spell out standards for participation in conformance with provisions of the law. It must also be convenient to develop and alter policy in the absence of established mechanisms for appeal. But, from the state's point of view, it is becoming increasintly difficult to engage in meaningful programmatic and financial planning without specific and reliable criteria.

While regulatory reform may address some of the current problems with the waiver, it is my belief that substantive improvements in long term care services for mentally retarded persons are ultimately dependent on additional legislative initiatives. At the very least, community-based services must be given equal stature in the Medicaid law so they are not viewed as a time-limited experiment. Ideally, the existing legislation would be amended to encourage and actually reward states for providing services in the home and community.

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(6) DR. MELZER, YOU SPOKE OF THE NEED TO INCLUDE PREVOCATIONAL TRAINING AS A REIMBURSABLE SERVICE UNDER THE WAIVER.

WOULD YOU ELABORATE ON THE BENEFITS OF THAT PROPOSAL?

Although not necessarily by design, existing federal practices systematically exclude many mentally retarded persons from work-related training. Because they are not considered to be employable, individuals with retarded development -- especially those with severe disabilities -- are frequently denied generic vocational rehabilitation services. At the same time, HHS will not authorize Medicaid reimbursement for training that is work-related, even though it is evident from the very nature of their eligibility, that beneficiaries are not capable of substantial gainful activity. This has been a long-standing policy, despite the fact that the enabling legislation for Title XIX of the Social Security Act included the provision of rehabilitation and other services to help low income families and individuals attain or retain capability for independence or self-care.

Federal officials have maintained that in the absence of current restrictions, excessive and inappropriate demands would be made on the Medicaid program for work-related training. The waiver, it seems, represents an ideal opportunity for exploring the benefits of providing prevocational services under very controlled conditions. Specifically, such services would be limited only to those beneficiaries who are otherwise eligible for the waiver, and the cost of prevocational training in combination with other waiver services, could not exceed expenditures for institutional care.

We recognize that some of our handicapped citizens will never achieve economic self-sufficiency. That, however, is insufficient reason to withhold the training which would enable them to spend at least part of their day in productive work.

If I can be of any further assistance to the Subcommittee and its staff, please let me know.

Sincerely,

Ronald Melzer

Ronald Melzer, Ph.D., Director
Community Mental Retardation Programs

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Senator WEICKER. Mr. Gilhool?

Mr. GILHOOL. Mr. Chairman, thank you very much for your invitation to testify here. Two of my colleagues from the law center in Philadelphia are with me at the table, Frank Laski and Judy Gran.

I began to pay attention to these matters in a serious professional way nearly 15 years ago when I represented the Pennsylvania Association for Retarded Children, as it was then called, shortly to become the Pennsylvania Association for Retarded Citizens, in the first right to education suit in this land, PARC versus the Commonwealth of Pennsylvania.

The directions of the PARC orders were, of course, adopted by the Congress and made the law of the land in the Education of All Handicapped Childrens Act. In recent years, my colleagues at the law center, and I have served as counsel to 25 of the protection and advocacy agencies throughout the late 1970's.

In those years, and still more recently, we have represented the associations for retarded citizens of Pennsylvania, Rhode Island, Connecticut and Michigan in litigation, all of it a part of the undertaking of the association for retarded citizens nationally to replace large, congregate care institutions with family-sized, structured living arrangements in the community.

I listened during the preceding 1½ hours that we have all been in this room and I want in my prepared remarks and in our conversation essentially to make three points. Much of the conversation to this point in this room, but for Commissioner Melzer's, Mr. Chairman, is conversation that seems to assume that the institutions which the Secretary finds appalling and which have been found abominable by every court that has looked on a record at the conditions in institutions in the rest of the decade-and-a-half of history of looking at the institutions—and what we find, indeed, is that the 70-year history is the same—the conversation seems to suppose that we could fix these institutions up and make them decent if only we investigate and enforce hard enough. That is, I would suggest, Mr. Chairman, wrong.

Second, the point I wish to make, Mr. Chairman, is that the very principles that guided this Congress in the formulation of 94-142 are the principles which must be now at last extended to the rest of the activities of daily living.

Finally, until this is done, Senator Weicker, neither HCFA nor HHS nor the State agencies will know where they are going.

The abominable conditions in public institutions and the injury, abuse, frustration and defeat they impose upon retarded people are a continuing and urgent national problem. Sometimes one fears that they are almost too constant and evil and have taken on some banality.

The picture today, however, as the Secretary's testimony confirmed, is the same in all material respects as this Congress found it to be in those institutions during its 3 years in the formulation of 94-142, in the formulation of the Developmentally Disabled Assistance and Bill of Rights Act of 1975, and in the Congress' formulation of section 504.

It is put into focus, I think, Senator Weicker, by Earl Butterfield's work for the President's Commission on Mental Retardation

in 1976. He looked at each of the 50 States to determine which were making the best effort to make their institutions decent.

In significant part, the ranking of the States that he came to reflected, of course, per capita expenditures. Butterfield found that——

Senator WEICKER. Do you want to repeat that?

Mr. GILHOOL. Yes, sir.

Senator WEICKER. Do you want to repeat that—I am sorry—that last sentence?

Mr. GILHOOL. Yes, sir. In significant part, Butterfield's ranking of the 50 States, according to the strength of their effort to make their institutions decent, reflected the measure of dollars spent per person in those institutions.

In his ranking, Butterfield concluded that only four States—Illinois, Connecticut, Michigan and Pennsylvania—were making superior efforts. Butterfield concluded, in his words, "If it were shown that these States provide inadequate care, then there truly would be a reason to seek completely different alternatives for this Nation's retarded people."

In each of those four States, Senator Weicker, the best of the States, that showing has now been made: in Michigan, Pennsylvania and Connecticut, conclusively, in Federal courtrooms; and in Illinois to the satisfaction of the Governor of Illinois, who last year closed the Dixon institution.

It is worth pausing on just one of them because the implications for what we do with this appalling situation that we have before us, I think, arise from an appreciation of the particular facts.

When the Pennhurst institution in Pennsylvania was at trial in 1977, the per person expenditure there was $27,000 per year. That institution ranked in the top 5 percent in expenditures. The number of direct care staff at that institution met regulatory standards.

Yet, the monthly injury summaries read like a battlefield report. Regression, significant loss of skills over the 21 years, on the average, that residents were in the institution was rife. That was in 1977, Senator Weicker.

In 1983, 5 years after the decree in the Pennhurst case requiring that everybody be moved to the community, but that in the meantime that institution be made as good as it can be made—in 1983, the per capita expenditures at Pennhurst had tripled. In 1982, they had reached $82,000 per person. In 1983, they were $67,000 per person. In 1984, they are $59,000 per person.

Pennhurst was, under that decree and the scrutiny of the Justice Department, including the criminal grand jury, the most carefully watched institution in the country. Dollars in extraordinary amounts were being spent; it had a superb superintendent. They tried very, very hard—I would submit harder than anyone can be expected to try on a consistent basis.

And yet, in 1983 and 1984, 9 employees were indicted by a Federal grand jury for 21 instances of intentional abuse of residents. The injury lists remained—and, remember, the population had been halved, but it remained proportionately at the same battlefield height that it had been at in 1977. And nearly a third of the residents left in Pennhurst—at that point about 500—had, between

1978 and 1983, regressed seriously; that is to say, on a base of 50 points on one of the measuring scales, they had lost 12 or more points while at the institution.

Secretary Heckler suggested we needed some studies. In contrast, however, a study which the Department that she heads has paid for over 5 long years has demonstrated that those who left Pennhurst have gained enormously in their skills, and the more severely retarded and otherwise disabled they were, the more they have gained.

That Pennhurst longitudinal study shows the community services to be significantly less expensive than the "services" at the institution, and it shows parents reporting enormously increased happiness on the part of their retarded relative and on the part of themselves, and significantly increased participation by the parents in the lives of retarded people.

When this Congress created the ICF/MR program in 1971, it said in the statute itself that active treatment was to be supplied. We heard this morning, now some 13 years later, that active treatment is not being supplied across the country.

Even, however, if on the paper record active treatment were being supplied, Senator Weicker, the further question arises whether active services in institutions can be effective to teach retarded people and to free their capabilities for a contribution to life.

The factual premise of 94-142 was, as I understand it, and the finding of this Congress was that every retarded person could learn important things, and what was required for each retarded person to learn was structured, individual attention and address.

That individualization enshrined in 94-142 and the individual education plans and the rest is, of course, also the central mechanism for learning and growing and participating by retarded people in all of the activities of daily life.

David Braddock's work in the mid-1970's told us what many suspected before that even the best of institutions—in his case, the institutions which had successfully sought and received accreditation by the appropriate accreditation council—were lacking in all the measures of individualization.

So far as the institutions are concerned and the investigations and all of the rest, one question, Mr. Chairman, does not seem reflected either in the Secretary's testimony or in the fact of the surveys, whether by States or by the national department and HCFA.

The fact is that, today, you can nearly not find a superintendent of a public institution for retarded people who will say anything but that the greatest number of people living in his institution should not be there.

Roger McNamara, the superintendent of the Mansfield institution in Connecticut, is illustrative: "I do not think we should renovate any more buildings at Mansfield Training School. We have renovated enough and we need to move toward moving people back into their communities."

The test for the decency or indecency of an institution does not require pages of a survey instrument. It is enough, straightforwardly, to go and live in one for a few days and ask yourself whether you or anyone you hold dear would want to live there.

And the counterpart test, of course, is to spend some time in a family-sized, structured community living arrangement and to ask the same question.

It is impressive that the Secretary should today pledge her department and the Health Care Financing Agency to vigorous enforcement of the ICF/MR standards. When those standards were created, however, the States were informed that by March 1977, they must be in compliance or they would lose their money.

When March 1977 came and went, they were told 1980, and then 1982. In 1982, the Inspector General of HHS itself, in an extensive program survey of ICF's/MR, reached precisely the conclusions which your staff reached in looking at 7 and which the Secretary reached in looking at 17 and another 8.

This morning's conversation impressed me, Senator, as nothing so much as reminiscent of State legislative hearings which I and my clients have sat through in State after State over the last two decades.

The attention is focused on the deaths and the rapes as if it were not a greater offense to humanity that severely retarded people with enormous capability for joy and contribution, for work and participation in the community, were so frustrated and defeated by the institutions.

The testimony this morning seemed to expect to find the history of the 70 years of these institutions which were created explicitly by the States, in haec verba, to segregate retarded people—It seemed to expect, as State legislative hearings every 3 or 4 years in the major States did, that once we look, then we will correct. The experience has been to the contrary, and indeed, Senator Weicker, the amount of attention and energy it takes to investigate and to monitor itself points in quite the opposite direction.

If neighbors and the community are the monitors, then we do not have to work quite so hard, though it is important, nonetheless, to hold HCFA's feet to the fire and to bring the Secretary to the pledge she made today, and to insist that State agencies should be careful.

Institutions come in and out of our consciousness, but their reality across these decades has been entirely the same, and it is in the Health Care Finance Agency's application of title 19, taking the money in all of its fullness—nearly $2.5 billion this year in Federal dollars—taking that money in all of its fullness to large, congregate institutions which are ineffective and which are more expensive, and resisting, refusing and, most recently with the home and community-based services waivers, entertaining the very nullification of those provisions of the law made by this Congress, effectively binding the States to the large institutions and preventing them from moving the dollars from the large institutions to the community, as virtually every State—certainly, every professional in every State—has avowed it wishes to do.

[The prepared statement of Mr. Gilhool and responses to questions submitted by Senator Weicker follow:]

STATEMENT OF THOMAS K. GILHOOL
CHIEF COUNSEL, PUBLIC INTEREST LAW CENTER
OF PHILADELPHIA

Thank you very much for your invitation to testify today. Nearly fifteen years ago I represented the Pennsylvania Association for Retarded Citizens in the first right-to-education case, PARC v. Commonwealth of Pennsylvania, whose decree the Congress adopted and made the law of the land in the Education of All Handicapped Children Act of 1975. In recent years with my colleague at PILCOP Frank Laski (who served as special counsel to the U.S. Commissioner of Rehabilitation during the years Title V was written), I have represented the ARC, Pennsylvania in the recently concluded Pennhurst case, the ARC, Michigan in the Plymouth case, the ARC, Rhode Island in the Ladd School case, and the ARC, Connecticut in the Mansfield case -- all of them a part of the undertaking of the Association for Retarded Citizens nationally to replace large, congregate care institutions which were created by the states in the first decades of this century with the explicitly invidious purpose, and the continuing destructive effect, of segregating retarded and otherwise disabled people with family-sized, structured living arrangements in the community.

I wish to make three points.

First, the abominable conditions in public institutions and the injury, abuse, frustration and defeat they impose upon retarded people are a continuing and urgent national problem. Only the

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banality of a too constant evil and eyes which refuse to see allow anyone to suggest that it's an isolated problem that is, in the ordinary course, being taken care of. From Willowbrook to Oklahoma, even now the picture is the same in all material respects. In 1976 for the Presidents Committee on Mental Retardation, Earl Butterfield ranked the states according to their effort to make institutions decent, in significant part measure by their dollar expenditures. Only Illinois, Connecticut, Michigan, and Pennsylvania were making superior efforts. Butterfield concluded:

> "If it were shown that these states provide inadequate care,then there truly would be reason to seek completely different alternatives for this nation's retarded people."1/

In each state that showing has now been made, in three of them conclusively, in federal courtrooms.[2/] At Pennhurst in 1977, although the per person expenditure there was in the top 5% nationally and the number of direct care staff met professional and regulatory requirements, the monthly inquiry summaries read "like a battlefield report." In 1983, when per capita expenditures already among the highest had trebeled and Pennhurst was the most carefully watched institution in the country, nine people were indicted by a federal grand jury on twenty-one counts of abuse of residents.

The federal statute requires "active treatment" in all assisted public institutions. 42 U.S.C.A. §1396d(d)(2). Yet nearly universally "active treatment" is not supplied. Service Delivery Assessment, Office of the Inspector General, Department of

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Health and Human Services, September 1982. When Title XIX was amended, Senator Bellmon was clear that not all institutions were to be assisted, only those

> "whose primary objective is the active provision of rehabilitative, educational and training services to enhance the capacity of retarded individuals to care for themselves or to engage in employment."

The Administering Agency was "expected ... to distinguish such facilities from those which are primarily residential." 117 Cong. Rec. 44720-44721. It has not, even on the paper record. And the paper record of compliance with the active treatment requirement itself falls far short of the question of whether active services in institutions are effective for retarded people.

The factual premise of P.L. 94-142 was that every retarded person could learn important things; what was required for their learning was structured, individual attention and address. David Braddock in his study of those institutions which had achieved accreditation and those who had applied for accreditation and failed -- in other words, the certified and self-selected "best of the lot" -- failed the measures of individualization.[3/] Yet individualization is precisely what is necessary for retarded people to learn and grow, the more severely retarded, the more necessary. The Longitudinal Studies of Implementation of the Pennhurst Orders[4/] shows that during five years (1978-1983) the people still remaining at Pennhurst despite the provision there, nearly unique in the country, of five hours of active program a day gained only a point

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on a base of approximately 50 in the adaptive behavior scale (statistically insignificant) while the retarded people who had left Pennhurst for family-scale community living arrangements and other training and work in the community, similarly disabled as those left behind, gained nearly 14 points during two or three years in the community, on the same base of 50, with those most severely disabled gaining the most. The Pennhurst studies show more services supplied in the community than at Pennhurst (9 rather than 5 hours) and at a substantially lesser cost than at Pennhurst. In smaller, family-sized settings, retarded people become more self-reliant, gain self-help and work skills, grow in interpersonal relationships, and increase family contact and family reports of happiness.

You can nearly not find a superintendent of a public institution for retarded people who will say anything but the greatest number of the people in my institution can and should be in the community instead. Roger McNamara, the Superintendent of the Mansfield Institutieon (Connecticut) is illustrative:

> "I do not think we should renovate any more buildings at Mansfield Training School. ... We have renovated enough, and we need to work toward moving people back into their communities."

The test, really, for the decency or indecency of public institutions is really simple and straightforward -- go live in one for a few days and ask yourself whether you or anyone you held dear would want to live there.

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For all the federal dollars flowing inexorably and all too untroubled to public retardation instituions, now more than four billion under Title XIX alone, surely we can do better. There are three reasons why we do so poorly -- why we impose so destructively upon retarded people.

One, there is something inherently wrong about a system that assigns to the states themselves the responsibility to tell the federal government that their institutions are injurious and abusive, that they do not provide active programs, that many in them do not need to be there -- in a word a system that supposes that the states themselves will tell the federal government that the federal government should not give the state the dollars. What happens now is a state surveys itself, finds deficiencies, writes a plan of correction, surveys itself again, finds its not meeting the plan, writes another and so on. ...

Second, the Health Care Finance Agency charged in 1971 with administering the §1396d program has throughout these thirteen years shaped and administered it contrary to the statute which is supposed to govern. Although the legislative history shows the Congress knew that retardation requires "rehabilitative, educational and training services", not primarily medical-model services and the statute itself speaks of "health or rehabilitative services", HCFA has persistently administered the program as a medical-model program. HCFA has refused to respect its own definition of institution, 45 C.F.R. §448.60(b)(1), and hence has refused funding

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family-sized structured arrangements. Although HCFA's own interpretive guidelines provided for ICF/MR's with 15 or fewer people, nearly all of the dollars have gone to large ICF/MR's. Although §1396(9(31) requires systematic independent review "of the necessity and desirability of the continued placement of [people] in such facilities and the feasibility of meeting their ... needs through alternative institutional or non-institutional services" -- in common language as the legislative history puts it "to assure proper placement," and "to assure that each [person] for whom Federal funds is provided is in the right place at the right time receiving the right care" 117 Cong. Rec. 44721 (1971) -- nearly never has HCFA enforced the requirement or transfer to the proper placement. Indeed by ruling proper family-sized community placements out of bounds for Title XIX funding, HCFA has bound the states into anachronistic expensive and ineffective large institutions. Even when the Congress has spoken with considerable clarity as it did in the Home and Community Based Services Amendments of 1981 intended by the Congress systematically to open effective family-sized community programs to Title XIX funding, HCFA has distorted the Home and Community Based Services Amendment to restrain rather than enable the states to move from institutions to community and O.M.B. threatens now to undercut the Amendment still further.

Third, federal enactments are inconsistent, incomplete, unclear or ignored. The counterpoint is P.L. 94-142. There the

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standard is specific and clear: the Congress mandated mainstreaming in education. At the least a full continuum of school settings is required, full especially on the integration end. As the Sixth Circuit Court of Appeals wrote recently

> "[The] requirement that mainstreaming be provided to the maximum extent appropriate indicates a very strong Congressional preference. ... In a[any] case where the segregated facility is considered [educationally] superior, the court should determine whether the services which make that placement superior could be feasibly provided in a non-segregated setting. If they can, the placement in the segregated school would be inappropriate under the Act."

Roncker v. Walter, 700 F.2d 1058, 1063 (1983) cert denied, ___ U.S. ____ (1983).

In contrast to P.L. 94-142's maximum integration imperative Congressional enactments on residential and other services, as they have been implemented (or not) by the executive and enforced (or not) by the Courts, have come to virtually nothing. Contemporaneously with P.L. 94-142 the Congress -- at least as I read the statutes and their histories -- did seek to legislate a similar imperative for residential and other services. Section 504 was intended, according to its primary sponsor, 'to end the virtual isolation of [disabled] children and adults from society," to reverse the history of their segregation in institutions. 118 Cong Rec. S32310 (September 26, 1972); 118 Cong. Rec. S9495 (March 22, 1972). The Bill of Rights provision of the Developmentally Disabled Assistance and Bill of Rights Act of 1975 on its face required

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that public funds -- federal and state -- be spent only -- on institutions or other residential programs which do provide services appropriate to maximizing the developmental potential of disabled persons in settings least restrictive of their liberties. As the Senate Report put it in 1975:

> "It must be recognized that ... the vast majority of persons now institutionalized should not be in those institutions at all. ... [M]ost of these institutions themselves are anachronisms and ... rapid steps should be taken to phase them out. Many of these institutions by their very nature, their size, their isolation, their impersonality, are unsuitable for treatment, education and habilitation programs."

S.Rep. 94-160 at 32-33.

As they pertain to institutional abuse and its destruction of disabled people, however, these Acts of Congress have been nullified, either bureaucratically or by the Court or both. Twelve years of bipartisan policy at the Department of Justice, consistently held and applied through three Administrations from Nixon to Ford to Carter, that the proper and effective cure for institutional abuse is the provision of alternative family-size community programs, has now been abandoned by Justice. For H.C.F.A., as for Justice, Section 504 might as well not exist. The High Court's treatment of Section 504 might as well not exist. The high Court's treatment of Section 504 in Southeastern Community College v. Davis, 442 U.S. 367 (1979) has imposed great caution in its enforcement by the lower courts. In Halderman v. Pennhurst State School and Hospital,

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majority determined that the Bill of Rights provision of the DD Assistance and Bill of Rights Act was "meaningless," merely "precatory" (a word never before applied by the Court to an Act of Congress), and "does not create any enforcible rights and obligations." Justice Blackmun writing separately decried the "perhaps dangerous precedent of ascribing no meaning to a Congressional enactment" and went on:

> "It seems plain to me that Congress, in enacting §6010, intended to do more than merely set out politically self-serving but essentially meaningless language about what the developmentally disabled deserve at the hands of state and federal officials."

The Court, however, held otherwise.

Commentators of varied persuasions have recognized in that decison by the Supreme Court "a major assulat on Congressional power"[5/] as well as the painful and still unanswered question "how states [can] disregard decencies so obvious that they hardly need Congress to define them..."[6/]

Thus, finally, on the central questions of these hearings there is as a practical matter no Act of the Congress which stands. If we as a nation are to end the 80 years of segregation of retarded and otherwise disabled people into distructive institutions and thereby both end institutional abuse and free the very considerable capabilities of severely retarded people for life, work and contribution to this society, a clear and strong legislative initiative by the Congress is required. Inconsistent directions need to be resolved to a common direction, excuses for bureaucratic or judicial nullification need to be taken away, and retarded people given their rightful place in the community. Only the Congress can do it.

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FOOTNOTES

1/E. Butterfield, "Some Basic Changes in Residential Facilities" at 15 and 22 in President's Committee on Mental Retardation, Changing Patterns in Residential Services for the Mentally Retarded. (R. Jugel and A. Shearer, eds.) (2d ed. 1976).

2/Connecticut Association for Retarded Citizens v. Thorne, (C.A. No. H-78-653); (Consent Decree filed May 9, 1984) (Mansfield case)

Michigan Association for Retarded Citizens v. Smith, 475 F.Supp. 990, affirmed 657 F.2d 102). (Plymouth case)

Halderman, et al. v. Pennhurst State School & Hospital, et al., 446 F.Supp. 1295 (E.D.Pa. 1977) affirmed 612 F.2d 84 (1979); reversed in part and remanded, 451 U.S. 1 (1981), affirmed 673 F.2d 628 (3d Cir. 1982) cert granted ___ U.S. ___ (1982);(Op. filed January 23, 1984); settled July 12, 1983.

3. D. Braddock, Opening Closed Doors (Council for Exceptional Children 197_).

4/ Pennhurst Longitudinal Studies, Temple University Developmental Disabilities Center, Philadelphia, Pa.

5/Owen Fiss & C. Krauthammer, "The Rehnquist Court: A Return to the Antebellum Constitution", New Republic 14-21 (March 10, 1982).

6/George Will, "When Government Fails", Newsweek 100 (May 11, 1980).

1. WHAT RECOMMENDATIONS WOULD YOU MAKE TO IMPROVE THE COMMUNITY WAIVER PROVISION TO ADDRESS THE PROBLEM OF THOUSANDS OF RESIDENTS IN INSTITUTIONS WHO SHOULD BE PLACED IN COMMUNITY SETTINGS?

The first recommendation is to amend the Social Security Act to replace existing fiscal incentives, which perpetuate costly, outmoded institutions, with incentives to the states to develop broad-based systems of community care. At a minimum, the states should be enabled to provide home and community-based services as a regular, permanent part of the state Medicaid program.

As long as the waiver is not a permanent part of the Medicaid system, the states simply cannot afford to use it extensively. The impermanence of the waiver -- and there is every indication that states cannot expect to have their waivers renewed at the expiration of the initial three-year pericd -- creates a serious fiscal problem for the states. If they want to use the waiver for deinstitutionalization, they face the prospect that federal reimbursement for the community programs developed under the waiver for former residents of institutions will not continue past the intial three-year period, leaving the state to pick up the total cost of those programs; whereas if those residents remain in the institution, despite professional judgment that they would be better off in the community, at least the cost of their care will be supported by federal matching funds.

The waiver is a permission granted to the states on a temporary case by case, county by county basis. The application process, which requires massive documentation, stringent HCFA

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review and often, repeated requests for supplemental information and extensive delays in rendering a decision on an application, is itself a powerful disincentive to the states to use the waiver as a source of funds for community programs.

The second recommendation is to ensure that the waiver is administered in a manner consistent with the statute.

Section 2176 requires that per capita Medicaid costs for individuals served under the waiver not exceed per capita Medicaid costs for those individuals in the absence of the waiver. That is the only cost limitation in the statute. The original House bill proposed to limit aggregate costs with the waiver to aggregate long term care costs in the absence of the waiver, but the Conference Committee rejected the House proposal and decided to use per capita costs, rather than aggregate costs, as the measure. Yet the Health Care Financing Administration, in its draft regulations and its administration of the waiver, has ignored Congressional intent and imposed conditions on the states which differ from and are inconsistent with those set forth in the statute.

The formula which HCFA requires the states to use in ~~capculating~~ Calculating their costs with and without the waiver is actually a formula for calculating aggregate long term care costs (the method rejected by the Conference Committee), rather than for calculating per capita costs. The formula is stated in the draft regulations at §441.303 (46 Federal Register at 48642). It is:

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$$\frac{(A \times B) + (C \times D)}{F+H} \leq \frac{(F \times G) + (H \times I)}{F+H}$$

where:

A=the estimated number of beneficiaries who would receive the level of care provided in an SNF, ICF, or ICF/MR under the waiver.

B=the estimated Medicaid payment per eligible Medicaid user of such institutional care.

C=the estimated number of beneficiaries who would receive home and community-based services under the waiver or other noninstitutional alternative services included under the State plan.

D=the estimated Medicaid payment per eligible Medicaid user of such home and community-based services.

F=the estimated number of beneficiaries who would likely receive the level of care provided in an SNF, ICF, or ICF/MR in the absence of the waiver.

G=the estimated Medicaid payment per eligible Medicaid user of such institutional care.

H=the estimated number of beneficiaries who would receive any of the noninstitutional, long-term care services otherwise provided under the State plan as an alternative to institutional care.

I=the estimated Medicaid payment per eligible Medicaid user of the noninstitutional services referred to in H.

Since the denominator is the same on both sides of the equation, it is identical with:

$$(A \times B) + (C \times D) \leq (F \times G) + (H \times I)$$

the formula for calculating aggregate long term care costs with and without the waiver: the method which Congress rejected.

HCFA has also:

-- Required that states assure that cost of waiver will be less than the arbitrary percentage (for example, 20%).

-- Used average ICF/MR costs (or a percentage thereof) as a ceiling for costs under the waiver even though the clients served under the waiver have come from institutions where the cost of care is substantially more than

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ICF/MR costs. This creates a disincentive for states to use the waiver to phase out their most costly institutions.*

-- Used average ICF/MR costs as a ceiling for each individual client's cost of services under the waiver, so that only clients in the 50th percentile, costwise, can receive waiver services.

-- Required the states to limit total medicaid and non-medicaid costs (Supplemental Security Income, Aid to Families with Dependent Children, and Food Stamps) to the cost of medicaid alone without the waiver. This contradicts the statute, which states that per capita medicaid costs, under the waiver, are not to exceed per capita medicaid costs without the waiver.

-- Limited reimbursement for community waiver programs to the estimates submitted in the waiver application, regardless of actual ICF/MR costs while the waiver is in effect.

Because HCFA has imposed these constraints in its administration of the waiver, and because of the nature of the waiver as an exception by special permission rather than an integral

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*For example, Pennsylvania has applied for $2176 waivers to provide community placements for deinstitutionalized residents of Pennhurst, an institution where the cost of care is among the highest in the nation, yet which a federal court found in 1977 did not "meet the minimum standards for the habilitation of its residents." In 1983, the average per diem cost of maintaining a person at Pennhurst was $190; the average cost throughout the state in public and private ICFs/MR was $100. HCFA demanded that Pennsylvania reduce the cost of services under the waiver to $87 per day and then even further, for clients who would cost $190 per day to maintain at Pennhurst, $108 of that in federal financial participation.

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part of the Medicaid program, the waiver as administered has not fulfilled Congress' intent to allow the states to use federal financial incentives to provide appropriate services to some of the thousands of persons in institutions who should be in the community.

2. WHAT HAS BEEN LEARNED IN THE DEINSTITUTIONALIZATION OF PENNHURST RESIDENTS WHICH HAS IMPLICATIONS FOR CHANGES IN FEDERAL POLICY FOR LIVING SITUATIONS FOR MENTALLY RETARDED PERSONS?

The first lesson of the Pennhurst deinstitutionalization litigation is the clear and dramatic benefits of deinstitutionalization for persons with retardation and their families.

A five-year longitudinal study of the impact of deinstitutionalization on Pennhurst residents conducted by Temple University is now nearly completed. That study has carefully measured the developmental progress of each Pennhurst resident while in the institution and later in the community. Families were surveyed before and after the decision to move their relatives from Pennhurst; comparative costs of services to clients in the institution and the community were analyzed.

In developmental growth, the study has shown that people are gaining much faster in skills in the community than they ever did at Pennhurst. For example, data measured over a five-year period for 93 people who left Pennhurst in 1980 shows that they gained, on the average, only 0.2 points on an adaptive behavior scale in two years at Pennhurst, and 13.5 points in the three years they were in the community. The study shows that people who were classified as profoundly retarded at Pennhurst have made the greatest gains in the community. In another study, 70 of the earliest movers from Pennhurst were compared to 70 matched "stayers"--persons who stayed at the institution. Those who moved showed highly significant increased functioning (over 8 points in two years) while those who stayed showed only marginal gains in

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development.

Interviews with family members before and after their relatives moved into the community showed that families overwhelmingly approve the decision to relocate once they see how much better off their relative is in a structured, family-like community living arrangement (CLA). The majority of families had opposed deinstitutionalization before the move to the community; but after their relatives had been in the community for six months, their attitudes changed rapidly. Families also report highly significant changes in their relative's overall happiness.

Cost comparisons have shown that the community costs less and is more beneficial than the institution. A controlled cost-effectiveness study which included measures of developmental progress and services rendered to clients showed that clients placed in CLAs were receiving substantially greater amounts of direct, structured, developmental services than their matched counterparts at the institution; yet the public dollar amount expended for clients in the CLAs was less than in the institution (institutional mean and median, $47,000/year; CLA mean $42,000; median, $36,000).

Other findings that have emerged from the systematic study of deinstitutionalization at Pennhurst:

-- Deinstitutionalized persons are better off in terms of the qualities of their living environments, on measures of individualized treatment practices and normalization.

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-- Deinstitutionalized persons receive many more services than people in the institution. People who moved from Pennhurst went from an average of 6 hours a day of developmental services in the institution to over 10 hours a day in the community.

-- According to their own reports, deinstitutionalized persons are happier in the community than in the institution.

-- Negative reactions of neighbors to group homes, where it occurs, fades with time.

The other lesson of Pennhurst is that if the benefits of community living enjoyed by the former residents of Pennhurst and their families are to be realized by others, a clear and strong legislative initiative is required. In the first Pennhurst decision (Pennhurst v. Halderman, 450 U.S. 1 (1981)), the United States Supreme Court held that the Bill of Rights portion of the Developmentally Disabled Bill of Rights and Assistance Act, 42 U.S.C. §6010, was "meaningless", "merely precatory", and that it "does not create any enforceable rights and obligations." In his separate opinion, Justice Blackmun referred to this as the "odd and dangerous precedent of ascribing no meaning to a congressional enactment," and three dissenting Justices stated that, to them, Congress was "deadly serious" in enacting the Bill of Rights provisions of §6010 and spoke "[a]s clearly as words can," that "§6010 cannot be treated as only wishful thinking on the part of Congress" nor "reduced to a mere statement of hope." Nevertheless, that is how the majority treated the Act.

Pennhurst thus shows that any ambiguity or lack of clarity in a Congressional mandate may be resolved against the legislature by the Supreme Court. Congress, when it legislates to promote the growth of community programs, must therefore speak with unmistakeable clarity.

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Senator WEICKER. Let me respond to your very thoughtful and very accurate statement. I certainly, first of all, to start the discussion going, would agree with you that the matters of physical abuse are only one part of the tragedy; that indeed the failure of the States to supply programs and education as is mandated by law is equally a tragedy.

I wish I could say that the community is a better monitor; I do not think it is. I think part of the problem that we have now on mainstreaming is the rejection of the community, if you will, of these particular citizens.

I do not think we have gotten, insofar as the communities are concerned, over the attitudes of 100 years ago in this area. I consider myself a fairly educated person, especially since I grew up in the era of Dempsey in Southbury—where I was in the State legislature and fairly knowledgeable on the more progressive aspects of what ought to be done in the case of mental retardation.

Yet, I had to go through a whole hearing in Hartford, CT, to be instructed on the difference between institutionalization and mainstreaming. It completely changed all of my ideas and thoughts on it.

I suppose what I am saying here is that we understand as a Nation Baby Jane Doe; you know, we visualize that. We all get exercised about prayer in schools, busing, Central America, and all the rest of these things. They are very real to us.

But believe me when I say this because this is my business, just as, counselor, yours is the law. Insofar as galvanizing this Nation, capturing its attention and getting its commitment to an inteiligent course of action vis-a-vis our retarded, it has not happened; it has not happened.

Now, you do not have to convince me that somehow we have got to move toward committing our funds to the mainstreaming activity. I also have to say to you that I do have a responsibility. You know, it must be very unfair. I have a Downs child that is 6-years old and, of course, many of the Downs children that are in the institutions in Connecticut are older children in their 20's and 30's and 40's.

And it must be very upsetting to those parents, quite frankly, to not have only had that strike of fate which brought to them a Downs child, but then to see the state of the art change. They can see how my child is progressing, and yet had we had that state of the art 20, 30, 40 years ago, their child would also be with them under far more preferable circumstances.

I do not think I want to abandon that parent in the sense of assuring that parent that their child or loved one will be taken care of. So the transition is difficult because you are absolutely correct in your statement that in terms of the happiness of the family and the welfare of the individual, mainstreaming is the answer.

But, please, tell that to all the parents and the relatives and friends of those that are receiving our care. Even they do not believe that yet, many of them, so the transitioning process—whereas you know exactly what we ought to be doing, your heart also goes out to some portion of the situation which calls for an entirely different handling of the matter.

All I can say is, No. 1, thanks for people like yourself and Dr. Melzer for accomplishing in the courts and accomplishing professionally in the institutions what needs to be done.

Somehow, I am trying to get a handle on this in terms of my chairmanship of this subcommittee and in conjunction with my colleagues and administrations—I do not just say the Reagan administration—to really bring this to the top of the heap to where everybody gets excited about it.

The problem, as you well know, in political terms is that there are not that many voters out there that are associated with the issue. So, please be patient. It is not that I do not understand or the committee does not understand what needs to be done.

But how do we get it? How do we get the cooperation of the Congress and the administration? This is what I was discussing with my staff just before you testified. The other half of this 94-142—tell me, Dr. Melzer, what is the Federal contribution to education for the retarded today as compared to what the Federal Government promised in the way of funding? What is it, about 12 percent we are giving now? What were we supposed to be doing by now?

Dr. MELZER. I think it was about 40.

Senator WEICKER. Forty percent, and we are at 12—it is 9 percent, the staff tells me, just in the education area, and we are supposed to be at 40 percent. I have got 31 percent to make up in terms of money, and God knows what we have got to make up in terms of what it is that we are doing, as you set forth. We are way behind in that.

My only comment to sum this up is that I realize and I am perfectly willing to concede that the investigations probably go over old ground, but somewhere along the line I am hoping to strike pay dirt here in the sense of arousing the conscience of this country to do both in terms of money and programs what, believe me, will bring happiness and hope and meaning to all those that are involved in this process that you and Dr. Melzer and others are so familiar with.

Mr. GILHOOL. I think, Senator, you are very close to striking that pay dirt. We have come a long way. It has been my judgment that if we are to go the next steps, the leadership must come from this body.

But consider how far we have come, and watch how bipartisan it is. Mario Cuomo announced in his state of the State address in January that the Willowbrook institution would be taken to zero. Governor Milliken of Michigan announced 2 or 3 years before he stepped out of the Governor's chair there that the Plymouth institution would be taken to zero, and a month ago it was and all of its 800 former residents are now in structured, supervised, family-sized community living arrangements in Wayne County, MI.

Indeed, Michigan now has more people in family-scale living arrangements than it has in the institutions—a position which my own State of Pennsylvania will reach after the Pennhurst case, which was settled 2 weeks ago—after that settlement is implemented.

In that case, Governor Thornburgh and his secretary of public welfare came forward and, after 10 years of very bitter litigation,

decided that they would close Pennhurst by July 1, 1986 and everyone would move to the community.

Mr. Melzer is in the same position in Vermont with respect to Brandon, over a reasonable period of time, and the rest. A part, I think, Senator, of what accounts for the now fully articulated insistence of those parents and families gathered together—and retarded people, I might add, gathered together in the associations for retarded citizens and in People First and the rest, is the experience with 94-142.

In 1970, 12,000 children of school age went to institutions because the schools were not open. By 1982, less than 1,500 people of school age went to those institutions. At the same time, we now have several generations of parents who have seen their severely disabled children flourish in the public schools and at home, and who will not now abide, once they reach adulthood, their children going to institutions.

While I am with parents, let me just speak to that very important matter that you addressed yourself to, and it is the pain and difficulty that parents, caught between generations when the state of the art has changed as it has, find themselves in.

I think perhaps the most useful thing that can be said about that, Senator Weicker, is to recite the outcomes of the very painful experience in the implementation of the Pennhurst orders to the point of this year.

In that period of time, nearly 600 people have left Pennhurst for the community. Of those 600, about 50 percent had active parents. Of the parents, Senator, at the point the move to the community was made by their relative, 52 percent strongly opposed the move.

Six months and a year later, Senator, the number of parents, with the experience in hand and seeing their child day by day not in their house, but in a community living arrangement and in other programs in the community—the percent of parents who strongly objected had diminished to 4 percent and the percent of parents who strongly supported had risen to 64 percent; support overall to 89 percent.

It is something like a Missouri "show me" experience, and for all it must be done with care and respect. But the bottom line is precisely as you put it, Senator. The facts are now in as to costs, as to decency, as to the enormous potential of severely retarded people to participate in the lives of all of the rest of us in this society straightforwardly.

What I think is so important about today's hearings is that for the first time in a lot of years—you have to reach pretty far back to remember—a Secretary has come here and her attention has been turned to the performance of the health care financing agency with respect to retarded and otherwise disabled people.

Many secretaries have been preoccupied with the rest of title 19. What is so important, given the attention that the Secretary is now giving to this matter, is that this Congress and the Secretary should come with some focus and clarity to what the standards are going to be by which these institutions are to be investigated and judged, and should come to some focus and clarity about what the remedies should be.

The Department of Justice back in 1972 and 1973 reached the conclusion, not a prior but based on their experience at Willowbrook and in Nebraska, that the remedy for institutional horrors was movement to the community.

In the 13 years that the health care financing administration has administered title 19, for no good legal reasons they have refused to face that fact. It is fine to threaten the cut-off of money, but if what that results in is forcing the States to pour more billions of dollars down the sink hole that the institutions are to no good effect, we have gotten nowhere.

Indeed, most of the States today are looking to the Congress and to HCFA—but now to the Congress because HCFA has been so constrained in its administration of the home and community-based services amendment—they are looking to Washington for leadership that will give the States the permission and the mechanisms to move the institutional dollars to the community with the retarded people.

Senator WEICKER. I am afraid that I am going to have to in a few minutes bring the hearing to a close because I have a leadership meeting.

Dr. Melzer, you have been very quiet. Is there anything you would like to add to the very eloquent statements of Mr. Gilhool?

Dr. MELZER. Senator, your staff was very explicit on the length of my prepared remarks, and this is not a trait back home. [Laughter.]

I would just like to comment on your observation about the anxieties of parents, and I have spoken to quite a few parents who were fearful about the move from the institution to the community.

I would say one of their greatest concerns was around the issue of stability. Many of them will admit that they think there are greater opportunities for their child in the community to learn the activities of daily living, but they wonder what is the stability of these programs over time.

And I would say that what is happening now should probably give them great concern. Here we have public testimony which indicates that we are spending some $4.5 billion on facilities that are not quite doing the job and that no one seems to be pleased with.

But at the same time, there is a move afoot to try to reduce substantially those alternatives to institutional care. I can assure you that there is some anxiety back in Vermont around what would happen to those 104 persons who were moved from the Brannon Training School if, in fact, we were not able to continue on with the waiver.

So I think as long as we keep giving people a double message about what is stable and what we are prepared to fund over the long haul, we can expect that kind of resistance.

Senator WEICKER. Let me assure you, only because I got off on my line of questioning and Senator Nickles had other questions, that I meant to get into the subject of the waiver and the regulations, et cetera. We are very much on to that and we will stay on to that with the Secretary. Nobody should have the slightest doubt that that is going to be ironed out to the satisfaction of the committee, and hopefully the Secretary, also, and also as far as the regula-

tions are concerned. Those will be forthcoming; they have not been. They are overdue 2 years in the request that we made on them.

Mr. GILHOOL. Just to name one, Senator, Pennsylvania has been waiting now a year for HCFA approval or disapproval on a waiver application filed last summer.

Senator WEICKER. All right. Let me see what we can do on that front, also. But I think you are now seeing, as you have known through the matters of your careers, the broad battle that is being fought. It is a very thin, red line, I will put it that way, to achieve a result that would be satisfactory to the people that you serve, to yourselves, et cetera.

[Additional material supplied for the record follows:]

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STATEMENT BY

AMERICAN HEALTH CARE ASSOCIATION

The American Health Care Association (AHCA) appreciates this opportunity to offer its views on the efforts of the Subcommittee on the Handicapped to improve the delivery of services in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). AHCA shares your commitment to quality care for the developmentally disabled. We commend the Chairman and the Subcommittee staff for their investigation of conditions in some of our large public institutions.

AHCA represents 8,600 licensed non-proprietary and proprietary long term care facilities, some of which are ICFs/MR. The typical AHCA ICF/MR facility is mid-sized, approximately sixty beds. The expertise and experiences of our private institutional membership provides the basis for the recommendations we offer.

Any examination of options to improve the delivery of ICF/MR services must consider the following:

1. For ICF/MR standards to be properly enforced, surveyors must be properly trained in all aspects of the program.

2. With the cost of ICF/MR care per recipient increasing by 20.3% from FY 1981 to 1982, it is imperative that more efficient delivery systems be developed.

Standards are only as good as the adequacy of their enforcement. AHCA recommends that surveys and inspections be made by individuals trained in the specifics of the ICF/MR program. Simply increasing the number of surveyors

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will not assure proper enforcement. The care delivered in an ICF/MR is more complex than care provided in a traditional ICF. Surveyors must be aware of this and should be able to judge the adequacy of the specialized services. The quality of the services can be related to the quality of the surveyors. Knowledgeable surveyors can serve not only to enforce standards but can also serve as a source of technical assistance. If the surveyor can first identify a serious deficiency and then offer assistance for correction, the ICF/MR and its clients will both benefit.

AHCA believes increased use of the smaller private rather than the larger state institutions would improve the objectives and efficiency of the program. Private institutions provide ICF/MR care for less money than the public institutions while providing quality and more personal care. Rehabilitative services are provided to residents on a smaller staff-patient ratio to assure greater attention to residents' needs and more emphasis on their skill development to live as independently as possible. The capability of the private institution to offer this level of services is due in part to labor and property costs of private institutions. Reimbursement is generally based on costs. The reimbursement system pays for public institutions built years ago to care for large populations, but now care for only a few hundred. Empty beds, buildings and excess property cost money to maintain. So do old, outdated buildings in need of major repairs and costly renovations.

Two studies on the costs of ICF/MR care support our recommendation to increase the private sector role in the delivery of services. Private ICFs/MR are reimbursed at $50 to $65 per day per client. According to the 1982 Public Residential

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Services for the Mentally Retarded by R.C. Scheerenberger of the University of Wisconsin, the FY 1981-82 average per diem costs in public facilities was $86.22. A second study, the 1982 National Census of Residential Facilities Summary Report from the University of Minnesota reports the 1982 average per day reimbursement per resident to be $45.15 for private group residences caring for 64+ residents and to be $85.84 for public group residences caring for 64+ residents.

Increased use of private ICFs/MR would save the system money and slow the escalating costs. AHCA believes this cannot be overlooked. The clients deserve care and the government must take steps to assure it can afford that care. Opting for the more efficient private institutions is one way to secure the future of the program.

Again, AHCA commends the Subcommittee for its commitment to the care of the developmentally disabled. We look forward to continuing our dialogue with the Subcommittee and its staff in working to improve ICF/MR services.

Senator WEICKER. I thank you very much for testifying. There might be some questions submitted to you for a response to the record. We particularly think that the country is very fortunate to have two persons of your ability and vigor and youth in this area. You are really very, very much needed.

The committee will adjourn.

[Whereupon, at 12:40 p.m., the subcommittee was adjourned.]

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